

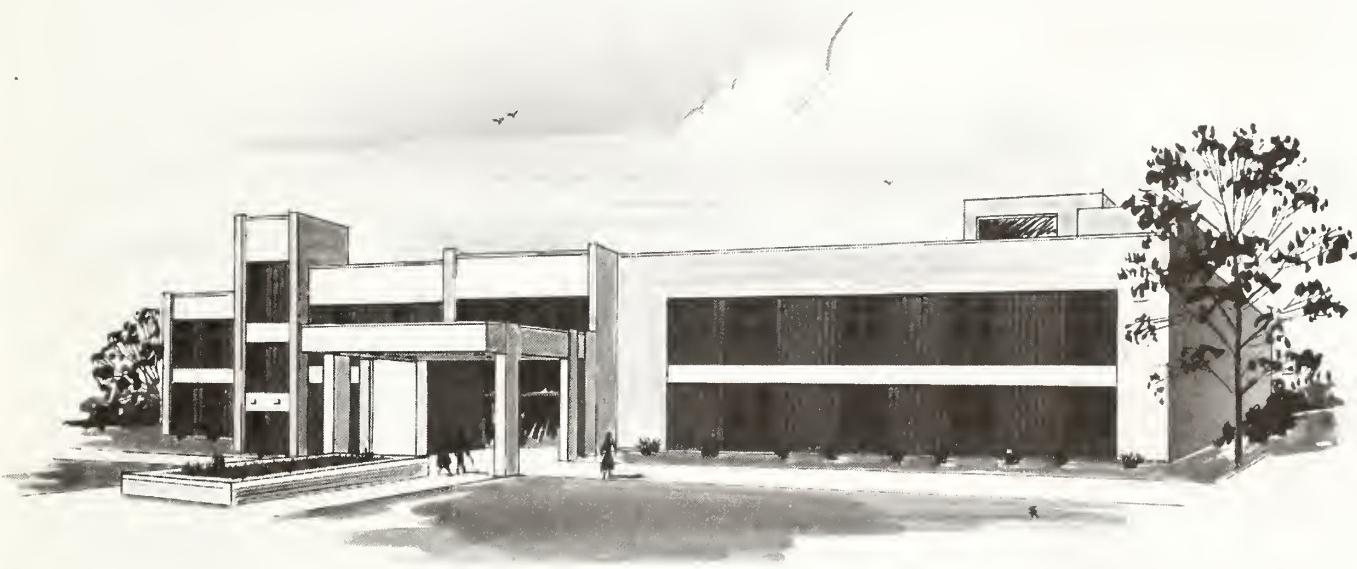


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NAT-CENT NEWS



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EDITOR — ROBERT J. SMITHDAS, L.H.D., Litt. D., L.H.D.
Editorial Assistant — Allison Burrows

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EDITORIAL
THE INTERNATIONAL NEWSLETTER
FOR DEAFBLIND PEOPLE

By Robert J. Smithdas, LHD, Litt.D, LHD

While I was serving my last term as chairman of the Standing Committee on Activities of Deafblind People of the World Blind Union in the early nineties, a motion was made to establish a newsletter, printed in both braille and large print, that would provide a source of information especially devoted to the interests of deafblind readers. The motion was carried and Patrick Murphy, the deafblind delegate from the United Kingdom, was appointed editor of the magazine.

Mr. Murphy accepted the challenge of editing the magazine and, for a few years, it was published annually. Then, for various reasons - lack of submission of materials and limited funding - it ceased publication. Mr. Murphy sent out a letter requesting readers to send him articles and

items of interest to deafblind people that could be included in the magazine, but the response was meager.

After an absence of three years, THE INTERNATIONAL NEWSLETTER FOR DEAFBLIND PEOPLE has resumed publication under a new editor, Lex Grandia. Skimming through the pages of its November 1996, issue I found articles related to various aspects of work for the deafblind, including a new communicator, similar to the Tellatouch, developed by Chris Lagarde of the Netherlands.

In braille format, the magazine is published in grade I braille to make it more accessible to deafblind readers in various countries.

Lex Grandia, the magazine's new editor, is 46 years old, a native of The Netherlands (Holland). Born blind and hard-of-hearing, he completed studies in theology and has worked in many areas. He worked for almost three years as a social worker for young people with

problems, gave courses in dramatizing Bible stories, and has written two books in the Dutch language. He states that because of his hearing loss, he decided "to use my hands more," and became a teacher in massage and a sculptor. He was active in organizations for the deafblind in Holland, where he started a newsletter for the deafblind in his country. Almost two years ago he moved to Denmark where he married a woman who is also very active in work for the deafblind.

He is currently the secretary of the European Deafblind Network (EDBN). He serves as editor of the network's newsletter and, as he states in his first editorial for the international magazine, he is becoming more and more involved in work for the deafblind field.

With his broad personal background and experience with combined visual and hearing loss, his wide range of experience in many areas of endeavor, and his

obviously intense desire to serve deafblind people, Lex Grandia is an unusual leader who can contribute much to the success of THE INTERNATIONAL NEWSLETTER FOR DEAFBLIND PEOPLE. Hopefully, readers will submit articles, poems and items of interest to the deafblind magazine so that it will serve as a medium for sharing information on an international level.

If you are interested in receiving future issues of the magazine, contact: Lex Grandia, Editor, Prinsessegade 28, DK 9400 Noerresundby, Denmark. Telephone 011 (to 45) 98 19 20 99 Fax: 011 (to 45) 98 19 20 57.

A WEAPON IN THE FIGHT TO SAVE SIGHT

The Foundation Fighting Blindness is a national research organization that studies retinal degenerative diseases, including retinitis pigmentosa (RP), macular degeneration and Usher syndrome.

Children with Usher syndrome are born with varying degrees of deafness, and later develop RP - a degenerative disease that begins with night blindness and progresses to a loss of peripheral vision.

To request a free Usher packet that answers commonly asked questions and provides updates on the latest research, please call The Foundation at 1-888-394-3937 or 800-683-5111 (TDD).

A SECOND "AIM" APARTMENT IN THE MAINSTREAM

By Barbara Hausman, Director Public Relations, HKNC
(Reprinted from HKNC UPDATE
Winter 1997)

HKNC recently rented and furnished its second apartment in the heart of the Port Washington residential community approximately two miles from its campus. While still in training a student may choose



HKNC student leaves his apartment.

to live off campus for six months and apply the skills he/she has acquired in all departments - communication, orientation and mobility, vocational services and independent living.

Everyday tasks such as menu planning, shopping for food and supplies, meal preparation, banking and budgeting (including paying all utility bills), housekeeping and household maintenance are practiced. Signal alert devices, such as the Vibra-Call are used as a wake-up alarm, doorbell, telephone and fire alarm.

The student accesses a host of community resources such as the post office, laundromat, drug store, and grocery store and must arrange for transportation, if needed, using volunteers or public services.

Critical Skills For Living in the Community Include the Ability to:

Seek help in the event of an emergency.

Communicate one's needs effectively to the general public.

Consistently and safely use all kitchen appliances and equipment.

Prepare meals safely and independently.

Budget, care for personal finances and be responsible for banking chores.

Use and maintain a signal alerting system.

Travel within the community as independently as possible.

Use problem solving and coping skills.

"The expected outcome of this program," noted Independent Living supervisor Phine Haugh, "is a sense of confidence and accomplishment for the participant. Perhaps for the first time the student experiences the reality of true independence, made possible by the

presence of a support network system. The AIM program is a final transition and integration into a more permanent independent living residence in the home community."

**EDITOR'S LINE:
LAURA BRIDGMAN**

By Michael Mellor, Editor
The Matilda Ziegler Magazine
September, 1996

In June 1996, at the invitation of Kathleen Spear, a deaf-blind reader I met at the 1995 NFB Convention, I attended the Annual Convention of the American Association of the Deaf-Blind in Tulsa, OK. This was my first time at this convention, and what a revelation it was to find several hundred deaf and blind people and their interpreters gathering together to exchange information, to learn about new technology - and to enjoy themselves. As always, it was good to meet Ziegler readers in

person.

How things have changed for people who are both deaf and blind since the time of Helen Keller, who was one of the first readers of the Ziegler Magazine. Her example made it realistic to think that people with this dual disability (lacking the only sense that can partially compensate for loss of the other) could receive an education and could lead satisfying lives outside institutions. While Helen Keller was a great pioneer, she was not the first deaf-blind person to receive a formal education - that distinction goes to Laura Bridgman (1829-1889).

It is true that a few deaf-blind persons before Laura had received some kind of education, but she was the first to be educated within a formal academic environment - the Perkins Institution for the Blind (now the Perkins School for the Blind).

Born in New Hampshire, Laura Bridgman came down with scarlet fever

when just two years old. Then a dangerous disease (it mysteriously became less virulent in the early years of this century, and is now treatable with antibiotics), scarlet fever killed both her sisters and made Laura extremely weak for three years! The infection took both her eyesight and her hearing, and enfeebled her senses of taste and smell. Any speech she had learned before the illness was forgotten.

Still, she was a bright little girl and mastered such domestic skills as sewing, braiding and how to work around the house, and she learned how to communicate her basic needs. She came to the attention of Samuel Gridley Howe (1801-1876) through an article about her in Barnard's Magazine by the head of the medical department at Dartmouth, who had heard about her from a student who had worked at the Bridgman's farm. Howe was the first director of the Perkins Institution for the Blind in Boston and he

took up the challenge of formally educating a deaf-blind individual. After Howe had visited with the Bridgmans, Laura was enrolled at Perkins in October 1837.

Howe's motives were complex. The young girl would undoubtedly provide a way to demonstrate his skill as an educator, but he also had a religious motive, for he was convinced that the soul was what distinguished humans from animals. He was sure that Laura could learn tricks, learn to make associations, just as a smart animal could. But he also believed that as a human being with a soul, she should be able to move far beyond the level of skill that animals can attain.

True to form, Laura readily learned to associate objects with their names spelled out in embossed letters. Was this real learning, or simply the kind of trick an animal could learn? Howe's religious beliefs were vindicated when Laura realized that she could use the letters of the

alphabet to spell out whatever she wished.

In Howe's words, "...the truth began to flash upon her - her intellect began to work - she perceived that here was a way by which she could herself make up a sign of anything that was in her own mind and show it to another mind; and at once her countenance lighted up with a human expression: it was no longer a dog, or parrot - it was an immortal spirit, eagerly seizing upon a new link of union with other spirits!"

Building upon this foundation, she was able to study spelling, reading, writing, arithmetic and geography. She learned to communicate with the manual alphabet and finger spelling. Writing in the square-hand script then taught at Perkins, she kept a journal, filling each page with neat pencil writing.

The life Laura Bridgman led at Perkins was busy and stimulating. Not surprisingly, when she returned home in 1852, because it was felt she had learned

all she was capable of, she could not adjust to life down on the farm; she had in a sense "seen Broadway." She became listless, lost her appetite and began to waste away. Her life was saved by her return to Perkins; once back there, she quickly regained her health and resumed her active life. As an excellent seamstress, she sometimes taught sewing - she was a very strict teacher - and she made most of her own clothes. She enjoyed crocheting and fashioning lace, which she sold.

The work done at Perkins to educate Laura Bridgman intrigued renowned English author Charles Dickens, who visited the Perkins Institution in 1842. He "did not deign to notice anything or anybody except Laura" one of the girl's teachers observed in her diary. Dickens's American Notes devoted 14 pages to a description of the school, and especially to Dr. Howe's pioneering work with Laura Bridgman. It was these notes that brought world renown to Dr. Howe, to Laura Bridgman

and to the Perkins Institution for the Blind.

When Howe died in 1876, he made provision in his will for Laura to remain at Perkins for the rest of her life. Some of the older Perkins girls were assigned in turn to share Laura Bridgman's room. Among these was one Anne M. Sullivan, who was partially sighted. She learned the manual alphabet to communicate with Laura.

Anne Sullivan could not have known that this contact would change her life: Forty years after Dickens's American Notes first appeared, it was his account of Howe's work with Laura Bridgman that made Helen Keller's mother realize that there was still hope for her daughter. She contacted Perkins, asking if help similar to that given to Laura Bridgman could be made available to Helen. Who did the director of Perkins assign to provide that help? One of the school's brightest recent graduates - Anne Sullivan.

Here is the direct personal connection

between Laura Bridgman and Helen Keller, and through her, I suggest, to all of those deaf and blind people gathered in Tulsa.

[In this account, I have drawn heavily on a paper by Kenneth A. Stuckey, Research Librarian for the Perkins School for the Blind and on Frances A. Koestler's **THE UNSEEN MINORITY.**]

ELLEN FINDS HER NICHE

(Reprinted from the
Perkins School for the Blind
Annual Report 1996)



Ellen Rys carefully folds the ivy-patterned pillowcases on her work

table beneath the glow of a high-intensity light. She stacks the pillowcases together and pulls on the large roll of plastic casing to her right. Placing the pillowcases between the two layers of clear plastic, she lowers the sealing heat bar. She uses a hand-held magnifier to verify the contents, written on an index card, then she puts a label on her finished package, writing on it: "2 king pillowcases."

"Ellen likes making things neat at her job with Marshalls," says Lynn Gillis, a job coach from Perkins. "She's impressive in her attitude and in her perfectionism."

Ellen puts the package in a box next to her table, checks her watch and signs, "Quitting time" to Lynn.

Ellen, 33, has been deaf and visually handicapped since birth, as a result of prenatal exposure to rubella (German measles). Lynn interprets what Ellen signs.

Since 1993, Ellen has repackaged merchandise - from towels and bed linens to jerseys and dress shirts - at this

off-price family retailer in Watertown's Arsenal Mall. She also processes merchandise: hanging clothes and affixing price tags to new merchandise. She works up to 20 hours a week.

At the beginning of Ellen's employment, Flo Peck, a low vision education specialist from Perkins Outreach Services, visited the Marshalls site to observe Ellen working and performed an environmental assessment. As a result, she made several recommendations to accommodate Ellen's needs. The high-intensity light that illuminates Ellen's workspace is one of Flo's suggestions, as is the hand-held magnifier that helps Ellen read particulars about the merchandise she's packaging. Another suggestion is more subtle: how to organize Ellen's workspace for convenience and safety. Scissors and pens are stored within easy reach, yet beyond her immediate work area. The result? Ellen is able to focus on her job, working quickly and efficiently.

"Ellen has a very focused personality," Flo says, "and she has a very work-oriented focus."

Flo also made recommendations to Ellen about making her apartment more convenient. The Perkins graduate had lived in an independent apartment with a roommate, who was also deaf and visually handicapped, but now lives by herself.

As Ellen walks toward the break room, the soft scent of gardenias breezes past. She goes to her locker for her handbag and mobility cane, then pauses at the break room table for some conversation.

"I enjoy my work," she explains. "I also like reading - true stories in history and shopping and meeting friends." She brushes back her shoulder-length strawberry-blond hair amid emphatic signing.

After another look at her watch, she apologizes, and says, "Now it's time to go." She collects her possessions, descends the stairs and moves quickly

through the store and the mall, and then to the adjacent Arsenal Park.

Walking in the warm summer sunshine, she finds a shady spot beneath a maple tree and sits to have lunch. She deposits her trash after lunch and, using her cane, walks through the park to catch a bus for home.

BLIND COUPLE'S ACHIEVEMENTS DON'T GO UNNOTICED

By Kelly B. Casey

(Reprinted from the TRIBUNE-REVIEW,
Greensburg, PA)

That David and Diann Popoleo are capable of facing challenges is nothing new. As the blind parents of 2 adolescent girls, they cannot avoid them.

But while the effort taken to raise Jessica, 15, and Rebecca, 12, has been somewhat taken for granted, the Popoleos' work outside their home has earned each of them special recognition.

David Popoleo, 43, was this year's runner-up for a statewide award from Pennsylvania Industries for the Blind and Handicapped, based in Harrisburg. He was chosen from among thousands of workers across the state for his outstanding achievement in coping with a disability, particularly in the workplace.

At another spring banquet, Diann Popoleo, 42, was presented with the Pittsburgh Blind Association's Dannielle Campbell award for "demonstrating courage and determination in the achievement of her goals," as stated in braille on a plaque.

Diann Popoleo is the area's first blind person with a hearing impairment to take telephone orders for Pizza Hut. "My goal is to make it easier for other people to do the same thing," she said.

Diann Popoleo didn't join the work force until well into her 30's, when her children were older and she decided "to do something for myself." The transition was

not easy. It took 2 years before she was hired, thanks in part to the efforts of PBA's Employment Support Services Program, which since 1986 has found jobs for 170 people with disabilities.

Diann Popoleo had sent out countless applications to no avail. She was quite discouraged when Pizza Hut called for an interview in January 1994. "I was the first blind person in Pittsburgh to do this job," she said. "I had to prove myself not only to Pizza Hut, but to (Employment Support Services) and employees with Pizza Hut. There were times I wanted to back out. It was touch-and-go for awhile."

But in 6 months, she was on her own taking orders at the Baum Boulevard shop in Oakland and punching them into a special computer supplied by the state.

Her guide dog sits under the counter while she's at work. Pebbles has been a big hit with her co-workers, but it took awhile, she said, for her co-workers to warm up to her. "They didn't know how to

talk to me," she said. "Now I'm just part of the team." Diann Popoleo said she enjoys the work but hopes to move up in the customer service industry. "I want more of a challenge," she said.

Her husband has a similar penchant for challenges. Despite his vision impairment, David Popoleo operates a drill press and riveting gun when he makes highway signs and other products at PBA's manufacturing division in Oakland.

His proficiency and dedication during a 20-year career with PBA did not go unnoticed. "Dave works on everything you ask him to do. He does it without question. And he catches on very fast," said John Sosnak, PBA's vice president of productions, who nominated David for the state award.

He caught onto the skills needed for parenting pretty fast, too. His wife taught him the basics, such as changing diapers and feeding infants. Diann Popoleo said she learned those skills from her 2 sisters,

whom she credits with making sure she did not miss out on the joys of motherhood.

Some family members, she said, did not approve of her having children. "Too bad," she told them. She admits she's not the perfect mom and is a bit overprotective. But the couple's children quickly adapted to their parents' limitations, she said.

She remembered that when Jessica was just 1 1/2 years old, the tot would tap her spoon on the table to let her mother know she was finished eating.

And when the girls were naughty and tried to run, Diann Popoleo said, she usually caught them.

THANKS FOR A CHANCE

By Sandra Lamb Stoffel, Student
Helen Keller National Center (HKNC)

I never thought that I would be attending college. I have Usher syndrome which is retinitis pigmentosa (RP) with a severe hearing loss. Years ago, I never

knew that there were support services to help individuals like me. When I attended regular public schools, I was the only hearing impaired child and never encountered others like me.

My parents didn't think of sending me to a deaf school. It was a struggle to communicate. I missed out on socializing and hearing others speak in class. I couldn't hear TV or music very well, so I made up my own

versions. My parents didn't know what to do with a child with a disability. They left me alone with the struggles of the world and I soon became withdrawn.

I wanted so much to be part of society but no one ever cared enough to try to include me. I had one hearing aid but I really needed two. I heard less than half of what was said and when I tried to communicate I felt embarrassed because



Sandra (R.) and her instructor, Michelle Smithdas (L.) work on braille skills.

sometimes I heard incorrectly and answered inappropriately. People thought that I was really strange. I spent my childhood being miserable, lonely and left out.

I managed to get through school and graduated with a B-plus average. I held various jobs, but I had a hard time interacting with the public. At age 18, I finally received two hearing aids and that made a big difference in my life. My speech and coordination improved, and I heard things for the first time - like birds singing, TV and the movies. I was so amazed. But still I was afraid to try college because I felt incompetent.

I didn't know that I had RP until my early twenties. An eye specialist informed me that I would be blind in one year. I was devastated! My family didn't know what to do and I was very depressed. I moved to Florida, got a job with civil service as a computer operator, and worked for about nine years. Obviously,

the doctor's prognosis was wrong. I was afraid to attend college, so I just existed, waiting for "the dreadful thing" to happen. I had no hope or support from anyone. I felt so alone. Counseling would have been beneficial because I felt so frustrated.

Two years ago my vision deteriorated again. I stopped driving and my job became too hazardous. I resigned before being laid off and returned to Kansas where my parents lived. I stayed for a year, helping my mom with housework and taking care of my grandma. Again I became depressed. My vocational rehabilitation counselor suggested that I enroll at HKNC for training.

On October 16, 1995, I entered a new environment. I had never met anyone like me before. I didn't know sign language. I saw tactile sign and that really blew my mind. I met a young man who used this mode of communication, but I was afraid to try it.

At HKNC I studied sign language and

learned to fingerspell. Happily, the young man that I had met is now my husband. We were married on July 6, 1996, and we lived in an apartment at the HKNC residence. Now we have moved to the campus of Hofstra University where my husband is studying for his degree.

I am still learning braille and sign language, acquiring independent living and computer skills and preparing for a job. The instructors at the Center have been instrumental in helping me gain self-confidence. I explored several jobs on-campus to decide which career path I wanted to pursue. I worked in the accounting and secretarial offices, the gift shop and in the residence assisting staff with students.

I worked briefly at AVIS headquarters in the community. I was interested in the medical field, so I enrolled in a local college to study medical transcription. It was hard. The college provided a notetaker which helped a lot.

There are many people who do not understand individuals who are HEARING AND VISION IMPAIRED. The white cane has made me feel more independent. It is an excellent mobility tool, though some people are still embarrassed by it.

I am doing well in college. I've earned four A's so far, but I have my most challenging course now and must learn medical terminology and anatomy. I type from tapes on a transcriber in which I can control the volume and pace. I find this fascinating and am encouraged that I am learning something I never thought possible before.

I am very thankful to HKNC and to my New York State counselor who have been so supportive and encouraging. I have never met so many people in such a short time who have given me hope for a better future. I no longer feel desolate and I try to enjoy what I CAN do rather than focus on what I CAN'T do.

READERS FORUM

From Diane Ayers, Mt. Airy, North Carolina:

I submit the following suggestions, ideas and problem solvers:

Always start the day on a positive note. Things seem to go so much better when you are in a positive frame of mind.

Tackle new learning experiences with the motto, "I Think I Can, I Think I Can" and then "I Know I Can, I Know I Can."

Go slowly when learning new things, nothing is more frustrating than to know you have to hurry up and get it done. Taking the time to do it and do it right always works to your advantage. And once you have learned something new, incorporate it in your daily living.

Make a list of the things you need to learn, then a list of things you want to learn. Alternate between the needs and wants for some diversification and you will find that you learn much easier if you can

take a break from the needs which are more physically exhausting, than the wants which are more pleasure oriented. Never stop learning, this can never be said enough.

It is to your advantage to learn as much as you can no matter what your age. Sometime in the future your learning experiences will pay off.

With my visual impairment I find that in everyday living one must get rid of the clutter. Start small with one room at a time. Clean out everything, yes, everything. I know this will take some time but you will be so grateful when you are done. Handle each item, and ask yourself if it really serves a purpose. If so keep it and place it where you know it will be when you need it. If not, donate it to a family member, charity or just trash it.

Please judge the items fairly, keeping something you will never use or have need of is senseless and is called clutter, and that is the object of this lesson to clean

things out. If it merits value and is in good shape give it away, if not trash it.

Of course, when you get done you will have a ton of things that are either donations or trash, but that's the idea. As you are sorting through, organize the things you are keeping for easy access. You will be amazed at how organized you will become.

Get in touch with organizations that can offer insight to any problems you are currently having. Some offer good suggestions or ideas that may prove helpful.

Look into technology to get in touch with the world, and about financing. There are programs out there to help if you contact them. Always ask how can they help you with information and financial assistance. Whether you are blind or hearing impaired, you need social stimulation as much as anybody.

Write to the NAT-CENT NEWS forum with things you have learned and share the

information, or if you are having a problem, there is an answer - never give up hope.

From Gary Shockley, Ethridge, Tennessee:

In your January 1997, editorial in NAT-CENT NEWS, you asked if we would like a forum included in the magazine for discussion of problems and needs unique to the deaf-blind. I think there are deaf-blind people whose vision and hearing are always changing through time, and such a forum would be great for exchanging information. I am on the deaf-blind list on the internet. You can learn many things on the list but discussions do not stay on the needs and problems of the deaf-blind. There is so much mail on the list that it takes a great deal of time to read through it all and find the information you want. A forum in NAT-CENT NEWS would be great!

From Don Aches, Springfield, Illinois:
I have been exploring sources that can

be helpful to deaf-blind people, and I have found many things that can be obtained free, like special cards for discounts in various shopping places or for discounts for senior citizens and the disabled. I would be glad to share this information with other readers and I would like to know if they have discovered similar sources that would be helpful. I will continue to explore these opportunities and, if readers are interested, I will write about them.

VOCATIONAL SERVICES AT HKNC

By Kathy Mezack, HKNC Vocational Services Coordinator

One of the fundamental activities within American culture occurs when an individual participates in some kind of productive work or gainful employment. Although individuals or social groups may assign specific values to different types of

work, these tend to be rather arbitrary judgments. One type of job may seem more prestigious than another, may have a higher pay scale, or may appear more like "real" work.



A work experience at Trunz Food Market.



Dana Cameron, student, does data entry work at AVIS.

However, such differences really are reflective of one's economic and social environment and not an overall national bias. The one concept that most Americans do agree on is the importance of some kind of work and avoiding unemployment. People who are unemployed for long periods are seen as a burden on society or undesirable.

The Vocational Services Program at the Helen Keller National Center (HKNC) is committed to assisting individuals who are deafblind in securing employment that is

substantial, rewarding and realistically commensurate with their abilities and aspirations. It follows that vocational training must develop as a very individualized process based on a person's actual skills and learning potential, always mindful of the home state's economy. Those who enroll in the HKNC Program originate from all parts of the United States and usually return home following the completion of their training.

Among human service professionals (and even among some sectors of the general public), it has become evident that people with vision and hearing loss, to any particular degree, are capable of some type of gainful employment. We are continuing the struggle to impart this truth to the nation as a whole.

A case in point. Rosie came to HKNC from Arizona after being unemployed for 18 years. She felt worthless, demoralized and had a hard time coping. She was concerned that she did not have the

aptitude, vision and ability to hold a job.

After completing a comprehensive vocational evaluation, Rosie expressed



Rosie enjoys living and working in Arizona.

interest and demonstrated potential to pursue training in food services. After two weeks of initial job coaching instruction in the HKNC residence kitchen, Rosie was

working independently. Her duties included food preparation, dish washing, cafeteria cleaning, sweeping, mopping and pot washing. After a short time, the supervisor of the kitchen hired Rosie as a dietary aide intern. Rosie's confidence and self-esteem soared but she still continued to doubt herself.

Since she wanted to broaden her experiences while she was in vocational training, Rosie requested a job in the food services department of a local hospital. Rosie was able to meet all deadlines and surpassed the time study data for competitive workers in the same position.

She realized that she really enjoyed her work and had mastered all the skills necessary to become competitively employed within the food services industry.

At HKNC we pay special attention to designing a follow-up plan when a student leaves the program. In Rosie's case several people came together to make a big difference in her life. Mike Guttierezz and Jim Schiller of C.O.P.D. in Tucson, Arizona, began looking for food services establishments where Rosie could fulfill her dream. Four possibilities were identified and while Rosie was still in training she and her vocational instructor began to fill out applications. The team approach and coordination of services in a person's home community is the key to successful placement.

Where is Rosie today? Two weeks after she returned home she started working at "Souper Salad" in Tucson, Arizona. She fulfilled her dream, gained

self-esteem and became a contributing member of her community.

When given the opportunity to express their talents and interests, most people will strive to achieve a level of success. Through vocational training, one can rebuild self-esteem, change behavior and affect a change in personal lifestyle. Work gives meaning to life, instills pride, defuses frustration and boredom and builds new confidence.

A WOMAN OF COURAGE - WITHOUT SIGHT AND SOUND

By Barbara Hausman, Director Public Relations, HKNC

Born and raised in Charleston, where her family and friends still reside, Rita Spann Morgan was hard of hearing at age 5 - "from a cold," the doctors said. She didn't know that 15 years later she would begin to lose her vision, as well!

During her school years, Morgan tried to ignore her hearing loss. "My mother always asked the teacher to seat me up front and I often had to ask people to repeat what they said," she explained. Undaunted, Morgan earned her GED and then her high school diploma.

In 1963, she moved to Moncks Corner just outside of Charleston where her brother is pastor of the Moncks Corner Church of Our Lord Jesus Christ. She worked as a nurses's aide at the Medical University Hospital in Charleston, and then moved to New York two years later, where she found a job as a nurses's aide at Nassau Hospital on Long Island and then at Brooklyn Jewish Hospital.

After earning a certificate in bookkeeping from Collegiate Institute in New York City, she applied her new skills to employment in an upholstery company in Brooklyn. A spunky and determined woman, Morgan successfully raised two children - a daughter who is now an x-ray

technician and a son who is an apprentice plumber. Four grandchildren add spice to her life.

But life took an unexpected turn in 1972, when Morgan was 29 years of age. After wearing eye glasses and hearing aids for seven years, an ophthalmologist diagnosed her vision problem as retinitis pigmentosa (a disease of the retina which causes loss of peripheral vision and can lead to blindness). He told her, "You should be blind already."

"I cried, he hurt me real bad, he told me something so cruel," recalled Morgan. At that point she had begun to bump into things, couldn't read regular print, tried large print and finally needed people to read to her.

In 1993, Morgan moved to Decatur, GA, and attended the Center for the Visually Impaired in Atlanta. One day while out on a mobility trip, "I felt so dizzy and had to sit on the ground to compose myself," said Morgan. "My case manager

called the Helen Keller National Center's (HKNC) regional representative, Susan Brooks, and they decided that I was a candidate for vocational rehabilitation training at their headquarters in Sands Point, New York."

"During my year's training at HKNC, I learned American Sign Language for the first time; I studied braille with an instructor who was deaf-blind herself; I was involved with other people who have vision AND hearing loss; but most importantly, I learned how to cope with deaf-blindness," said Morgan.



Rita works on the computer
in the Technology Room at
HKNC.

"Once a week I was employed at the Nassau County Social Security office, about a half hour from the Center, performing data retrieval work. I helped with tasks in the Public Relations Department and at the Residence on campus. I was so happy at HKNC!"

According to Morgan's case manager at the Center, Suzanne Ressa, "Rita was extremely focused during her months here. She knew what her goals were and she set out to achieve them. She helped to reorganize student areas in the Residence - lounges, computer and TTY areas - and she did a really fine job! She always had something cheerful and uplifting to say, like her 'Thoughts for a Day' which she occasionally submitted to the HKNC's in-house newsletter:

"Monday: Call someone on the telephone and see how they are doing.

Tuesday: Be thoughtful of others.

Wednesday: Be more of a listener than a talker.

Thursday: Practice random kindness and senseless acts of beauty.

Friday: It is better to look ahead and prepare than to look back and regret."

Plans for the future? You bet! Morgan is returning to her own apartment in Decatur where she is very active in her church and in the community. She has held several offices in the Decatur Mission Church of Our Lord Jesus Christ - president of the women's auxiliary and women's choir, chaplain and treasurer of the missionary department, and she even taught Sunday School to young teenagers.

"I love talking to people and helping in any way that I can," said Morgan. "I plan to attend a 15 week course about computers at Georgia Tech and hopefully will be employed part-time," said Morgan.

But with a twinkle in her eyes, she revealed a secret passion: "I would really like to own my own restaurant, 'Rita's Place', featuring homestyle southern cooking!"

ON THE JOB

By Barbara Hausman, Director Public
Relations, HKNC
(Reprinted from HKNC UPDATE
Winter, 1997)



N.B. with her HKNC case manager, Audra Moran.

N.B., aged 29, has Usher syndrome I, a genetic condition combining congenital deafness and progressive blindness due to retinitis pigmentosa. Born in Guyana, she lived in the United States for three

years before she was referred to HKNC.

During her 1 1/2 year training program she became proficient in ASL, a major growth from the limited 100 signs she first knew. A part-time job at a local department store, McCrory's, enabled her to experience the world of work. Living in an independent living apartment on campus for 10 weeks, she was able to

apply her classroom skills in a functional setting.

When N.B. completed her HKNC program, Case Manager Audra Moran and Work Training Specialist Lisa Feliciano searched for an appropriate employment site in her home community, Flushing, NY.

"It's a bit uncommon, but we made a match quickly," said Moran. "We walked into 'the Gap', spoke to the store manager and were referred to Regional Manager Laura Reisman who later interviewed N.B. for a job as stock person." N.B. lived with her aunt and could walk about 20 to 30 minutes to work. HKNC's mobility staff oriented her to the route and her new environment. Community services were provided by VESID and a job coach from the Lexington Center for the Deaf was assigned to assist N.B. in her supported employment position.

"During the first week or so, I visited N.B. each day, but I gradually cut back my support to three times a week, then twice

a week, and soon there will be no visits, depending on how comfortable we both feel," said Job Coach Beth Langan. "Next, a 'follow along' job coach from the Lexington Center will be assigned for general support, if needed, twice a month.

"Since she began, N.B. has been doing so well. Though her hours vary - 8:00 or 10:00 a.m. to 4:00 p.m. - she is always on time. She finishes quickly and does a thorough job. She puts on the censor tags, folds the jeans in a special way, hangs clothing on the racks and sorts by size. She feels very proud when she performs her tasks correctly.

N.B. uses communication cards or simple gestures with her co-workers, has given them name signs and taught them a few basic ASL signs. She feels comfortable at work and doesn't hesitate to ask for help."

Management has been very cooperative and offered to make simple adaptations such as adding an extra light in the

stairwell to the stockroom and placing a hook at the top of the stairs for her cane. "N.B. does a great job," added one of the Gap Managers, Maribel Perez. "She works quickly, understands the various tasks and takes directions very well."

BOOK REVIEW:
BEYOND THE DOUBLE NIGHT
By Michael Mellor, Matilda Ziegler
Magazine for the Blind, Editor's
Line, February, 1997.

The striking achievements of a deaf-blind man once called the smartest man in America were almost forgotten. James Morrison Heady (1829-1915), was born in Spencer County, Kentucky, the son of a country doctor who was also a farmer. He lost the sight in his right eye at age six, when a wood chip hit it. Far from damaging him psychologically, this misfortune buttressed his spirit; he kept his positive attitude and refused to be deterred

from living like other boys his age.

He was very intelligent, likeable, noted for his sense of humor, and fascinated by everything and everybody. His father, furthermore, was determined that his son would receive the best possible education, even though there were no public schools in those days. It was in the course of this education at a "common school" - one in which several families pooled funds to support a teacher in a one-room school - that the next misfortune literally struck the youth. Watching his schoolmates playing leapfrog, the bare foot of one boy struck him in the left eye and destroyed his remaining eyesight; at age 16 he was totally blind.

His education nevertheless continued. He was enrolled at the Kentucky Institution for the Education of the Blind in Louisville, where he followed a highly disciplined, indeed gruelling, schedule that today's children would surely complain about. He had abundant self-confidence, and it was

said he walked about like one who is not blind. In this he was perhaps not too wise.

He suffered many injuries and falls, and when his pony threw him headfirst into a pile of rocks, the long-term consequences were dire - he developed a ringing in his ears that became worse over time and slowly made him deaf.

Undeterred, Mr. Heady led a life of astonishingly varied achievement. He invented a "talking glove" - an alphabet glove that allowed sighted-hearing people to spell words into his hand. An amazing feat of mechanical engineering was his Diplograph, which could emboss paper with the Roman alphabet, or New York Point or braille at the flip of a lever.

Ever anxious to make reading materials available to those who could not hear or see, he built a prototype of a steam-powered embossing press and hired a wagon and driver so he could demonstrate it around Kentucky. So convincing were his presentations that he

raised \$6,000, a huge sum, which enabled the American Printing House for the Blind in Louisville to buy a full-size steam-powered press.

As if this were not enough, he composed poetry (in excellent hexameter) and music, wrote adventure and love stories, and corresponded with Laura Bridgman, Helen Keller and John Greenleaf Whittier. In his later years, when his family moved from the country to Louisville, he became a familiar figure in town with his bizarre red-lined cape and long beard.

His creed was, "I love God and little children." Children loved him in return because of the wonderful stories the man they called "Uncle Morry" would gladly tell them. Weather permitting, he would sit down on the sidewalk and, surrounded by attentive, appreciative children, tell his stories.

He was also a friend of the distinguished Flexner family of Louisville

who were drawn to his achievements, to his good humor, wonderful spirit, his compassion for the human predicament and his non-judgmental nature.

It is hard to believe that Mr. Heady's footprints in the sands of time were almost obliterated. We owe a huge debt to Ken D. Thompson for rescuing this incredible man's story from oblivion. The Ziegeler's records show that James Morrison Heady was a subscriber from March 1909 until his death in 1915.

BEYOND THE DOUBLE NIGHT, by Ken T. Thompson is published by the Buggy Whip Press, P.O. Box 459, Taylorsville, KY 40071, at \$15.95. The National Library Service will issue this book in braille and cassette, but the publication date has not been set.

HERE AND THERE

A signature guide, made of black plastic and the size of a credit card, fits neatly

over the signature line of standard checks. It is handy for endorsing checks or for any situation where a signature is required. For convenience, the guide may be attached to a keychain.

To obtain one of these guides, send a self-addressed, stamped envelope and \$1.00 to: Rev. George Gay, 1002 Johnson Street, Pasadena, TX 77506.

* * * * *

Advantage Graphite Folding Canes are designed with an optimum balance weighting system. The canes feature precision ground joints, which increases rigidity while reducing noise and vibration. All canes come equipped with firm rubber golf grips wrist loops, replaceable polymer tips and easy to see reflective tape. Canes are available in lengths from 36" to 60" in 2-inch increments.

For prices and further information, contact: Revolution Enterprises, 6335 Nancy Ridge Drive, San Diego, CA 92121.

Tel.: (800) 352-5232.

* * * * *

Tagarno, Inc., manufactures several CCTV reading systems, including Tagarno CCD, Tagarno Color CCD, Tagarno Mini-CCD, and the Tagarno School-CCD. The latter device is equipped with a motorized camera that is operated with a joystick. With a split-screen function, a visually impaired student can read text under the external camera, or read the text on the chalkboard in the classroom or read from both at the same time.

For complete descriptions and prices for all Tagarno reading units, contact: Tagarno, Inc., 615 Otis Drive, Box 761, Dover, DE 19903. Tel.: (302) 734-9630.

* * * * *

The New Jersey Association of the Deaf-Blind, Inc.'s Our-Co Industries (a small business employing people with deaf-blindness) is now producing necklaces on

which you can spell your name or favorite words in braille. The necklaces come in two lengths - 18" and 22" - and have glass beads in 4 different colors: blue, green, purple and red. The cost for each necklace is \$4.00 plus \$.50 per letter. For more information or to place an order, contact Joann Capone at (908) 805-1912.

* * * * *

It has finally arrived: Video highlights of the "Reaching Out Conference 1996" sponsored by the Deaf-Blind Association of Toronto, Canada, which took place in June, 1996. To order your copy, send a check or money order payable to D.B.A.T. for \$10.95 plus \$3.50 shipping and handling to: Box 405, 422 Willowdale Avenue, Willowdale, Ont. M2N 5B1 Canada. Please allow 4 to 6 weeks for delivery. All proceeds from the sale of this video go to D.B.A.T.

MY HANDS

(Editor's Note: The following poem, MY HANDS, was written in Portuguese by a deaf-blind woman living in Brazil and was translated into English by her close friend, Mrs. Nice Tophozi de Saraiva, late director of the Anne Sullivan Foundation, Sao Paulo, Brazil.)

What could happen to myself without my hands?

Since I can't see, neither can hear,
smell nor can taste.

They are my hands that take me up
in order to share with the world,
the contacts and, by this way
I take care of them so carefully.

They bring me news, expressions,
reactions from people.

They permit me to touch the kind faces of
the children, to kiss them
and to observe them.

How I would love to make a poem to my

hands.

I would like to be a poet
at least for a few moments
in order to be able to glorify the importance
of my hands.

I imagine sometimes
that they are talking,
the right hand telling:
I work without resting
day and night.

My lady can't see,
and I substitute her eyes.

When she walks,
I go further yet to prevent her
from some obstacle,
to show her the way!

I'm always ready to guide her.

And when she wants to feel the persons,
if they're happy or sad,
if they're ugly or beautiful,
and if she wants to feel the kindness of a
child.

It's me who gives her these messages!
And the left answers:

through myself,
she gets aware of everything that happens
around her
talks to friends,
and relatives, and all those
who have good wills
to learn the manual alphabet.

Through myself,
that I'm her ears,
she can feel the guitar's vibration
and its melody
while her friend Celso
plays for her.

Answers the right one:
It's me who brings her mouth
the food.

When she's sad and leaves her tears
dropping,
it's me dissembling
who runs to dry her face.

When she feels some pain
I go to the exact place and show it to her.

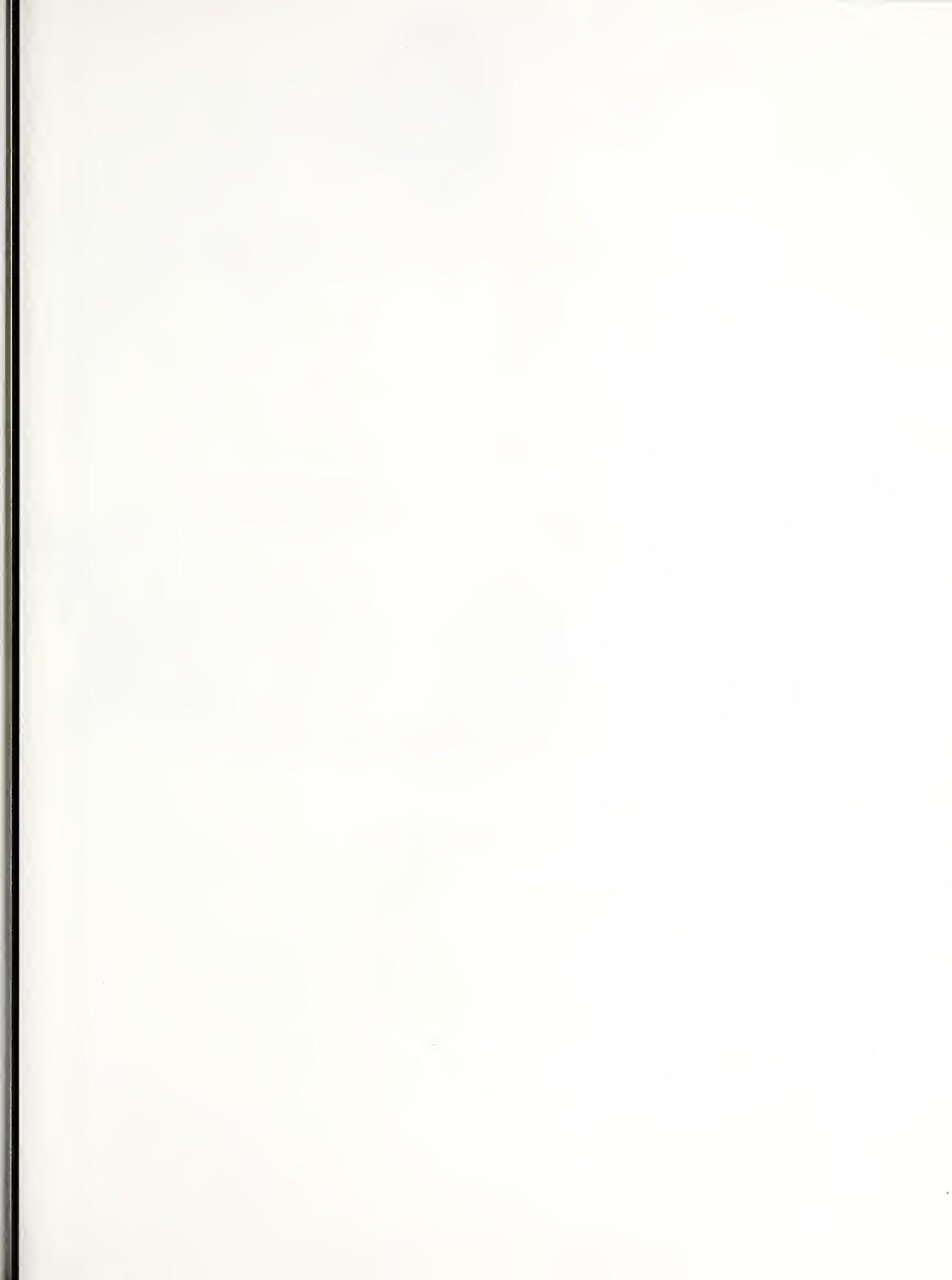
Answers the left one:
It's me who tells her everything.

I work actively.
The persons shake me too strong
and I have to correct them
about the right position that they can
touch me.

I receive the alphabet letters
and sometimes I get tired because
some of them run excessively,
some others are too slow.

But, always I do my work, sister.
And both agree:

We're both very important
even in spite of being separate
we perform our part,
together we collaborate,
to let her read her braille,
to make her handicrafts,
and to go following her way,
in this life moving ahead.



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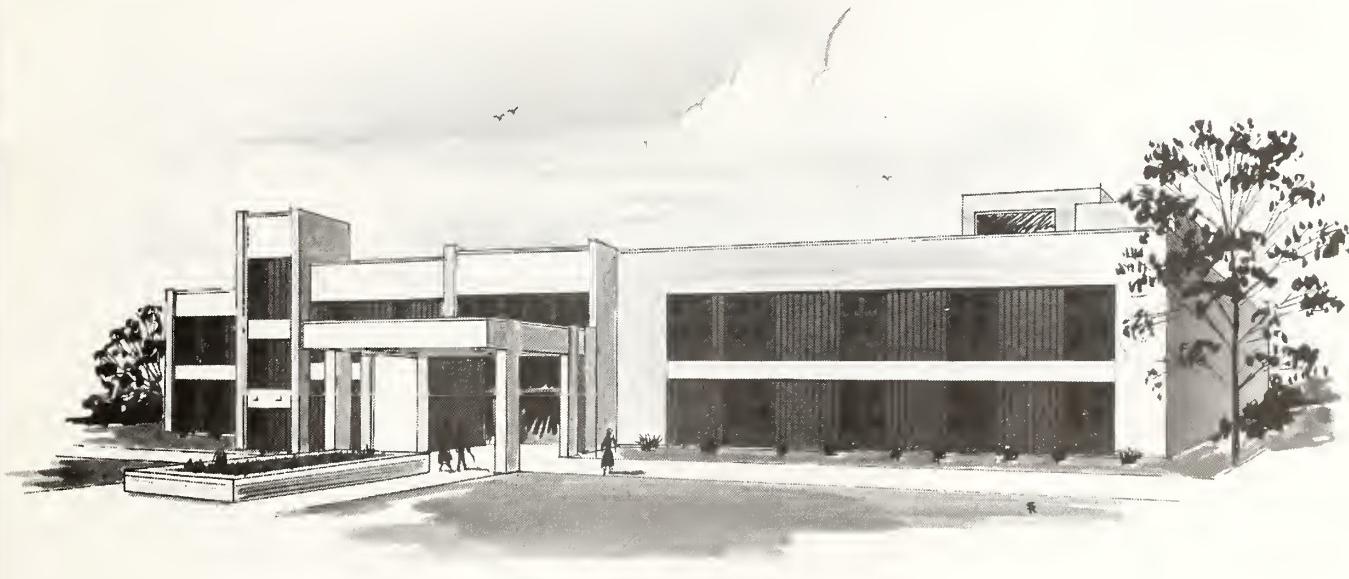
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EDITORIAL FROM A SMALL BEGINNING

By Robert J. Smithdas, LHD, Litt.D, LHD

Recently I had the opportunity to read two on-line communications from C.C. Davis, the Helen Keller National Center's (HKNC) southwestern regional representative. He indicated that there was a sudden interest in the origin and history of the Helen Keller Deaf-Blind Awareness Week that HKNC sponsors annually. It brought back memories of the small beginnings of an event that has grown into a national fixture.

Shortly after the Center established its permanent campus in Sands Point, New York, in 1975, we became aware that the general public, as well as most rehabilitation and service agencies, knew very little about deaf-blindness or how many deaf-blind individuals existed in the nation's population. We had been aware of this problem for years, but now it

became suddenly urgent to find and identify deaf-blind individuals so that the Center could offer the kind of training that would give them a greater measure of independence and self-reliance. Ultimately, it was decided that the best solution would be to approach the United States Congress and ask it to declare a national deaf-blind awareness week.

In 1984, we went to Washington as planned and approached several key members of Congress. In offices of members who were absent or unavailable, we left a letter I had composed, written in both print and braille, asking for their support. The following year - 1985 - the congressional resolution passed and a proclamation was issued making the week in which Helen Keller's birthday falls the Helen Keller Deaf-Blind Awareness Week.

Since that small but auspicious beginning, HKNC has been responsible for promoting the annual Helen Keller Deaf-Blind Awareness Week.



Thomas Gulotta, Nassau County (NY) Executive (right), presents a Proclamation in honor of Helen Keller Deaf-Blind Awareness Week to Dr. Robert J. Smithdas (left).

Special credit for the success of the week goes to Barbara Hausman, the Center's director of Public Relations who, year after year, has developed a new and meaningful theme that describes the needs of people who are deaf-blind, their successes and achievements. Posters, public service announcements and other

forms of public media help to spread the word.

Her effort and skill in organizing and planning each year's new promotion of Helen Keller Deaf-Blind Awareness Week has indeed produced recognition of people who are deaf-blind - their potentials and needs.

It is interesting to note that Great Britain now has an awareness week and that there are now international groups exchanging expertise and information about deaf-blindness and people who are deaf-blind.

WORK EXPERIENCE MEANS LEARNING SKILLS

Every year in June, around the time of the national Helen Keller Deaf-Blind Awareness Week, the Helen Keller National Center recognizes community businesses and services that have cooperated in

providing opportunities for work experiences for its students.

The Center's Vocational Training Program provides students with realistic on-site training in a variety of job settings, develops their potential skills and builds their confidence in their ability to succeed in the real world of employment.

HKNC is indeed fortunate to have a group of work experience providers who, year after year, have given generously of their time and patience to make its' Vocational Training Program meaningful and successful.

Following are two presentations that were made at HKNC's annual recognition of our work providers this past June this year - the first by Nancy Brakenridge, a former student from Indiana, and the second by Kathy Mezack, Vocational Services Coordinator.



Nancy Brakenridge and Joe McNulty, HKNC director, enjoy the celebration.

My name is Nancy Brakenridge and I am a student here at the Helen Keller National Center. I came here after having lost my full-time job of 16 years working for the same insurance company in Chicago. I have Usher syndrome II, which is the

combination of retinitis pigmentosa and hearing impairment. Retinitis pigmentosa is a disease which affects a person's field of vision.

When I first began my job in Chicago, I was able to see the whole office at a glance. At the time of my termination, my field of vision had decreased to the point that I could no longer see the whole computer screen without scanning it first.

But I have some very good news to tell all of you. With the help of my case

manager, Betty Scott, and my work experience teacher, Darcel Jackman, I was able to enroll in a one year program at Molloy College. I am now a certified medical transcriptionist. A medical transcriptionist is a person who can print out on paper through the use of a computer what a doctor dictates orally on tapes.

Now, it is one thing to say you are certified - it is quite another thing to go out into the real world and actually do the work for which you are certified. Fortunately for me, I have had the wonderful opportunity of doing a 24-hour internship under the supervision of Theresa Maltese in the Pathology Department at St. Francis Hospital. I am so truly grateful to her for giving me back the confidence I so much needed. Not only am I confident but I am anxious to return to my home in Indiana and find a permanent job transcribing. I am not ready to stop working yet.

So thank you, Theresa, for opening your door to me. I see here today that there are others like you who have opened their doors to other students like me. I can only hope that in this shared experience of working with each other that more and more deaf-blind people will be able to not only enter into the work force but to be able to stay within the work force for as long as they want. Thank you all.

* * * *

Kathy Mezack:

We are here today to celebrate Helen Keller Deaf-Blind Awareness Week and to honor all of our community work providers.

I look forward to this event every year because we are often so busy with day-to-day things that we don't have enough time to truly recognize the contributions everyone in this room has made to the students. It is so important that we formally gather as a community to reflect

on the many successes of the past year. The Helen Keller National Center and the surrounding community have been working together for more than 10 years to support the vocational goals of the many students that come here from all parts of the country, as well as the international students we have served.

Preparation for employment is a critical part of helping people to develop a sense of personal dignity and to realize their full potential. We have one very specific objective - to prepare students to enter or re-enter the work force. The Vocational Services Program at the Helen Keller National Center is committed to assisting individuals in securing employment that is substantial, rewarding and realistically commensurate with their abilities and aspirations.

The students at the Center acquire work experiences on- and off-campus in single placements or, at times, in small groups. They successfully work in a host

of jobs from data entry, to assembler, to teacher's aide.

There are two ingredients in business: capital and labor. Given sufficient quantity of capital and quality of labor, a business has what it takes to succeed.

Quality of labor force issues are affecting every type of business, every size, in all sectors. Employers' biggest headache these days is personnel. Finding, training, and retaining qualified hard-working employees is key to success. When you have the right people who have the right attitude, you can produce, adapt to changing markets, be competitive, make a profit. But how to find such workers?

Through a diversified work force.

"Diversity" is more than a buzzword - in fact, there is an untapped pool of labor just waiting to be discovered. Its members are ready, willing and able to work, although you might not have recognized it yet because the makeup of this country's labor force has changed.

"Diversity" may be today's buzzword, but what it means is the majority of newcomers into the workplace from here on out will be of differing races, national origins and other characteristics - such as having disabilities.

Study after study, most of them commissioned by employers who didn't believe this labor force change was happening, show that workers who have disabilities consistently perform equal or better than their non-disabled colleagues.

One of the best studies, a 30-year effort by Dupont, found that loyalty is high and turnover rates are low. Eighty-six percent of employers say that attendance of the workers with disabilities is above average.

We have a labor force to offer the community that is skilled, motivated and most importantly being trained in old-fashioned work values that make any employee an asset to their organization.

Perhaps we can all look back and

remember our first interest in work. We all wanted a chance to prove ourselves. We believed we had something valuable to contribute, and if only someone would believe in us, we could prove that we were a reliable and motivated employee. We at the Helen Keller National Center are committed to the mission of advocating for the students - to support their efforts and desire to work like everyone else.

Vocational training in the community is the objective - the way to give the students opportunities to develop marketable skills for eventual full-time placement. You have played a big part in the vocational success of the students and have been active members of our support team. Today we want to recognize your contribution to our Vocational Training Program.

Several new work providers have joined us this year. We thank and welcome these new members into the ever-growing partnership between the Helen Keller

National Center and the community. We honor your commitment to serve as advocates of the students. We thank you for supporting deaf-blind individuals who have the skills and motivation to work and to become more independent members of their community.



Kathy Mezack (center) relaxes with two work experience providers from the Sands Point Nursing Home.

When given the opportunity to express their talents and interests, people will strive to achieve a level of success. Through vocational training, one can rebuild self-esteem, change behavior and

affect a change in personal lifestyle. Work gives meaning to life, instills pride, defuses frustration and boredom and builds new confidence. Thank you for sharing that belief with us.

HENRY BUZZARD BECOMES A PRIEST

Henry Buzzard of White Plains, New York, was formally ordained to the priesthood at St. George's Episcopal Church, Manhattan, New York, on June 28, 1997.

Henry, a retired librarian from the New York School for the Deaf in White Plains, has been involved in religious work with the deaf at St. Ann's Church for the Deaf in Manhattan since 1983. He was a lay reader when he assumed sole responsibility for church management after its previous pastor left.

After consulting his bishop and failing to find a qualified priest to take over

management of church activities, Henry arranged for interpreting services for the deaf members of the congregation during services for hearing members of the church until he found a replacement, Reverend Roy Brown, who travelled from New Haven, Connecticut, twice a month to conduct church services.

Henry, with his postgraduate degrees in hand, was authorized by his bishop to study for the Episcopal priesthood under Dr. Roger Pickering of All Souls Church for the Deaf in Philadelphia. He travelled by train to Philadelphia every month for two and a half years. He then took the examinations required for candidates for ordination, and was accepted by the Episcopal Diocese of New York.

Henry was ordained a deacon on August 26, 1996. He took charge of St. Ann's Church for the Deaf in New York City, the oldest church for the deaf in the country, established in 1852 by Reverend Thomas Gallaudet oldest son of Thomas

Hopkins Gallaudet. The church holds religious service at 11:30 on the first and third Sundays of each month at the larger St. George's Episcopal Church on 16th Street near Third Avenue.

Henry, who has Usher syndrome, volunteered for five years to work among the deaf-blind population in New York City. He was a member of the American Association of the Deaf-Blind for several years and served a term as its second vice-president before he began to study for the ministry.

Henry, 76, is deaf and visually impaired. He is married to a deaf woman and they have two adult children.

Henry says he owes his success to perseverance and determination to stick to his goals, and also to his faith in God.

A YOUNG MAN OF COURAGE - WITHOUT SIGHT AND SOUND

**By Barbara Hausman, Director
Public Relations, HKNC**

His vision and hearing were perfect. Then, at age 16, Michael Stutelberg became blind and hard of hearing. The official diagnosis was Mitochondria disease, MELAS syndrome, a progressive degenerative condition which results in multiple severe sensory impairment. His symptoms included cognitive processing difficulties and memory problems which affected his ability to receive and understand information consistently, loss of sensitivity in his fingers and toes and a somewhat impaired sense of balance. Four years later, after enduring two strokes, Stutelberg became totally blind. In November, 1996, he lost his hearing.

When he first arrived at the Helen Keller National Center (HKNC) in September 1995, Stutelberg still had some residual

hearing and used a hearing aid. Staff was aware of his prognosis. Their job was to prepare him for living as independently as possible and for re-employment back home in Midland, Michigan.

"On the day that my husband and I dropped Mike off at the Center, I cried and thought, 'These people are strangers and we're 1000 miles away,'" recalled Mrs. Stutelberg. "I didn't know how he would respond because this was his first experience away from home and we are a VERY close-knit family. It was difficult for Mike at first. We spoke every day. Mike came home for all holidays and we visited him in Sands Point in between. It was the hardest thing, but ended up as the BEST decision we had ever made. True, he missed his family and his brothers, but he learned that he COULD do it!"

Though Stutelberg used his voice, he needed to develop a unique communication system to receive information since he was unable to learn braille or become fluent in

American Sign Language due to his sensory loss. Slowly and through repetition, HKNC staff introduced signs to him tactually. Because he found it difficult to discriminate the different signs, his communications instructor, Stacey Sullivan, began to shape the signs into his hand which he could feel with his other hand. Then Stutelberg would voice what was said.

He and Sullivan also developed a sign language book containing two lists of signs, first by category, second by alphabet, which was continually updated for Stutelberg's family as he learned new words. These acquired skills were critical because two months after leaving HKNC was when Stutelberg lost his remaining hearing. He and his family were prepared. Though it was another traumatic time in his life, Stutelberg and his family could still communicate with one another and express their love and support.

"That's the beauty of what we do here

at the Helen Keller National Center," noted his case manager, Suzanne Ressa. "Mike always had a positive attitude as well. He never dwelt on his deficits. He loved to work out, but his real passion was sports!"

During 11 months of training, Stutelberg tried several work experiences out in the community - one at a local food co-op and another at a sporting goods store in preparation for returning to his hometown job at the Dunham Sporting Goods store.

A beautiful relationship flowered between Stutelberg and an HKNC volunteer, Milton Warren, who read him his local paper's sports pages and letters from home several days a week. One could see them strolling arm-in-arm down the corridor joking and chatting together.

"My friend Mike is a great sports enthusiast whose excitement for the Minnesota Vikings, LA Lakers, and then the Phoenix Suns usually called for a fond debate since I am a Giant and Knick fan,"

remembers Warren. "We had a wonderful time together. I could always count on his usual greeting, 'Hello, wise guy,' and my response was, 'OK, Mike, where is the buck you owe me?'" Their friendship continues through a caring correspondence between Mike and "Uncle Miltie" since he left the Center.



Michael Stutelberg (L) and "Uncle Miltie."

Today, Stutelberg lives in Midland independently from his family in a private house with another person with a disability. Twenty-four hour staffing provides needed support. A professional assigned from the Commission for the Blind and Visually Handicapped (CBVH) works directly with Stutelberg assisting in morning daily living skills and then accompanying him to work to help as his job coach.

Staff at his residence were specially trained by HKNC's Sullivan to reinforce his communication system. His state counselor, Richard Carlson, and HKNC case manager, Suzanne Ressa, secured the needed funding to ensure this smooth transition from HKNC to his home community where he lives with dignity and independence surrounded by family and friends who love him and a community which truly embraces him.

As a final update, this past April Stutelberg received a cochlear implant, a

device designed to provide sound information for people who have a profound sensorineural hearing loss in both ears and show no significant benefit from hearing aids. This may enable him to hear environmental sounds or even spoken language. "We don't know what the final results will be," said his mother, "but we hope and pray that this will work for him."

Everyone at HKNC shares Mrs. Stutelberg's sentiments!

POTENTIAL JURORS FIGHT TO SERVE: Two With Disabilities Battle for Rights Under Constitution

By Robert Baird

(Reprinted from the Pittsburgh Tribune-
Review, Pittsburgh, PA)

They don't look much like minutemen from the Revolutionary War. And, although jurors aren't called "at a minute's notice" like the colonial volunteers, their

service - lasting hours, days or months - has proven just as vital to the preservation of our basic rights. Those who answer a summons to serve, keep alive the rights guaranteed by the sixth and seventh amendments to the Constitution.

"I tell them they're the ones who make it work," said Thomas Rakaczky, jury program supervisor in the criminal division of Allegheny County Common Pleas Court. The time and tedium that often accompany jury service might not seem worth it to some, but it keeps the system from grinding to a halt, he said. And some citizens who avoid service could take a hint from prospective jurors with infirmities, disabilities and hardships who answer the call, Rakaczky said. "It's important to them," he said.

Jo Ann De Long, who is hearing-impaired, went to U.S. District Court in Pittsburgh in 1988, to fight for the right to serve on a Blair County jury. "She got the ball rolling," said Diane Gallagher,

of Pittsburgh Hearing Speech and Deaf Services Inc., which provides sign language interpreters for the deaf jurors who have served since DeLong paved the way. U.S. District Judge Donald Ziegler ruled DeLong could serve because Blair County received federal revenue-sharing money. That meant DeLong was subject to the Federal Rehabilitation Act, which the county violated by a blanket exclusion of deaf persons.

The claim that DeLong's exclusion violated the 14th Amendment guarantee of equal protection under the law did not have to be decided, said her attorney, Robert Lape, of Roaring Springs, Blair County. "It was extremely difficult emotionally for her," Lape said. "She was horrified that her deafness alone was considered such a handicap that she could not serve."

Not many people would fight to do something that is a public service. "She wanted to show that deaf persons are

competent individuals," Lape said. "I didn't see why it was such a big federal issue. Pennsylvania has a law that a juror must read, write, speak and understand the English language, and that was a matter of interpretation for each judge."

"After I won in court, there were many deaf people on jury duty, but not me," said DeLong in a telephone interview through a special communication device called TTY relay. "Maybe after I won they think I had a big head. It wasn't my fault. Ha. Ha. I got a letter for going to jury duty. While I was in court, the lawyer didn't pick me. Maybe they heard all about me winning the case," said DeLong, whose husband and brother-in-law have since been called for jury duty.

Paul Richard McGann Jr., who is deaf and blind, was called for jury service last spring in the Allegheny County criminal division. He had been called earlier in the civil division, but wasn't picked either time. "I'm honored to serve on jury duty when

I'm called," said McGann, 43, of Brookline. "I do know it is important to me - and I would sacrifice anything to attend."

During his appearance for jury duty, McGann, who has worked at the Western Pennsylvania School for Blind Children for 23 years, placed his hands atop the hands of a sign language interpreter, in the process known as tactile interpreting.

McGann, who was born deaf and lost his sight later, said attorneys believed he couldn't see the evidence. But McGann said because he had vision previously he knows "what items look like because I was educated to understand the description."

"I use interpreters as my eyes and ears, said McGann, a former vice president of a national deaf-blind association and co-founder of the Pittsburgh Deafblind Lions Club. "My jury service went along fine."

The jury trial system has its roots in England, where neighbors were summoned to settle property disputes and draw

property lines. But court officials said the fast-paced modern life has given rise to the belief that other matters are more important than jury duty.

Karen Stebbins, Allegheny County jury coordinator, said there are jurors who could use financial hardship to avoid service but "believe enough in the system to lose money and come in and serve. Some don't want to be bothered, but it's an inconvenience to everyone and we tell them we need your open-mindedness."

One who didn't have to be convinced was Melvin Rosenberg, 58, of Squirrel Hill, a federal administrative law judge. He reported for jury duty in May in the Allegheny County civil division, after an earlier call to the criminal division. "This time I knew enough to bring a magazine. We're expected to comply with summonses for jury duty," said Rosenberg, who shuffled his schedule to make it possible to serve on jury duty.

Rosenberg, an attorney who hears

social security and medicare cases, never made it to the jury box. He said he was passed over in one case and a settlement was reached in another. By a juror's mere presence, defendants in both criminal and civil cases are prevented from switching from settlement discussions to demanding a jury trial when they know a panel isn't available.

Allegheny County President Judge Robert E. Dauer, who has been called but not chosen as a juror, has issued warnings and levied fines for contempt of court for citizens who failed to appear. "It's hard balancing how many (jurors) to call in each day. A few times there are too many. At times we have to go to the civil division and get jurors. But, so far, I haven't had to pull them off the escalator at Kaufmann's."

Despite the challenge of getting enough jurors, there is almost no one who suggests that jury trial be abandoned. But reforms are proposed for the jury-selection process. Dauer favors doing away with

peremptory challenges, which the prosecution or defense use to reject a certain number of prospective jurors. The lawyers can use such challenges without explaining why. "Most frequently they are used in a sub-rosa manner to eliminate minorities from juries. It happens all the time. It's obvious to me and to the other judges. There is no reason for it." But the elimination of peremptory challenges would cause attorneys "to scream bloody murder" and has little chance of becoming law, Dauer said.

The Allegheny County Jury Commission and Urban League of Pittsburgh are trying to diversify the pool of potential jurors. Other ethnic, senior citizen and business organizations also are expected to add names to the lists being used for licensed drivers, voter registrations and telephone directories.

ABOUT DIALOGUE MAGAZINE

If you would like to be "in the know" about all the latest products, assistive devices and services available to blind and deaf-blind people, you will want to subscribe to DIALOGUE MAGAZINE. Articles written by visually impaired authors deal with family matters, home and garden care, sports and recreation, adjustment to living with sight loss, and fiction and poetry. DIALOGUE has such a wide variety of topics and is so full of useful information that readers never like to miss an issue!

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IN THE MAINSTREAM --- SKILLS FOR THE HOMEMAKER

By Phine Haugh, Supervisor,
Independent Living (IL), Helen Keller
National Center

The teaching and acquisition of homemaking skills can be a complex process for many individuals. Presented with the dual sensory loss of vision and hearing, the performance of any activity

can become an overwhelming task. Whether acquired through congenital or adventitious means, the age of onset of the dual-sensory condition combined with the nature and severity of the loss determine the ability of the individual to participate in and to benefit from the total rehabilitation process.

The procedures involved with learning or relearning a skill involve many concepts. One may conceptualize the sum of the steps involved in an activity, yet be unable to execute even elemental components of a given task as a result of a vision and/or hearing loss. The process of rehabilitation strengthened by support from family, friends and caring professionals, can enable the individual who is deaf-blind to gain the skills and confidence necessary to lead full personal, social and economically productive lives.

As Steffy McQuiggan, HKNC student, mother and homemaker expressed, "My feelings swell with so much emotion; but I

become more comfortable daily in my growing ability to succeed through learning in a flexible one-to-one educational environment."

The purpose of this article is to provide the practitioner/rehabilitation professional with an understanding, attained through developmental practices, to teach safe, effective and efficient work methods to individuals who are deaf-blind. It is hoped that such practices will afford all individuals the opportunity to live as independently as possible in their desired living environment. Total sensory input is stressed as a means of gaining control over one's environment. Through skill development, fear is reduced, stress is lessened and a sense of confidence and accomplishment is achieved.

Individual variations within the deaf-blind community are considerable. As professionals, the need to recognize and to tailor person-centered instruction for every individual is not only imperative, but the

key to success. Teaching independent living skills to people who are deaf-blind or who have limited vision and hearing employs the use of all of the senses, including maximizing the use of any remaining or impaired sense to compensate for the lack of hearing and sight.

In order to effectively comprehend the process involved with the teaching of functional skills and the transfer of knowledge to people who are deaf-blind, a number of considerations emerge:

- Communication method employed during instruction.
- Method of instruction and time frame involved.
- Sensory development.
- Differences in the deaf-blind population.
- Expectation of the individual who is deaf-blind.
- Expectation of the rehabilitation professional.

- Acceptance of the rehabilitation process.

Communication Method Employed During Instruction

There are many methods by which the deaf-blind person can receive instruction: speech via the auditory mode or with the aid of assistive listening devices and/or lip reading techniques, print on palm, fingerspelling, use of gestures and body language, sign language, tactile sign, braille, raised line print and additional print materials of various size. The preferred method should be that which facilitates communication with the greatest of ease as expressed by, or determined through, working with an individual.

Communicating the information required to teach a functional task involves a sequence of steps. For example, to teach methods used for the preparation of a hot beverage: 1) an initial explanation of the steps involved to complete the task must

be introduced and provided prior to beginning the activity; 2) time must be allowed not only to communicate this information to the individual but also to allow him/her to process the information given; 3) the individual must convey an understanding of the instruction and demonstrate the ability to remember and to apply the direction to the task at hand; 4) various methods of instruction may need to be individually explored with visual and/or tactal demonstrations provided as part of the lesson sequence; 5) the introduction of technology or aids and devices such as, in this instance, the use of a hot beverage maker and liquid level indicator will need to be demonstrated in a visual or tactal (hand-over-hand mode) in addition to the given explanation of the task.

Additionally, to enhance expressive and receptive communication, external and environmental factors such as lighting conditions, background noise and proximity to the individual may need to be

considered.

Method of Instruction and Time Frame Involved

Individual modifications in instructional methods will depend on the degree of vision and hearing loss, additional disabilities and previous experiences in performing independent living tasks. The person who is experiencing a decrease in vision or who is newly blinded will need to allow for an increase in time to complete most activities. Many persons allocate up to one and a half of the time period previously allowed to complete household or daily living tasks. Additional time is needed to acquire, process and to respond to information, to proceed with confidence and to become proficient with alternate work methods utilizing input from all of the senses.

The person who is deaf or hard of hearing can master most independent living tasks with minimal difficulty and will

benefit greatly from visual stimuli, available auditory input and applied experience. When a decrease in vision and/or hearing occurs causing one to become deaf-blind, the degree of loss that affects both senses will determine the method of instruction and the time frame involved to complete a task. The more severe the manifestation of the combined loss, the greater the need for tactful communication, demonstration and instructional work methods. Thus, the time factor required for the acquisition of any skill will greatly increase.

The age of onset of deaf-blindness, additional disabilities associated with the condition, ability to comprehend and relate to language instruction and previous life experiences or afforded level of independence collectively influence the method of instruction and the time involved to master a task. A functional environment which synchronizes the learning process with time/task appropriate settings can enmesh training goals from

every domain with a transdisciplinary instructional approach. This has proven to alleviate the difficulties involved with time restricted instructional settings.

Sensory Development

Sensory development for the individual who is deaf-blind implies training in the use of low vision aids, assistive listening devices and retraining in the use of the eyes, ears and all body senses. Particular emphasis is given to the senses of touch, taste and smell. Of paramount importance, is the need to gain or regain a feeling of accomplishment and confidence in one's ability to cope and function successfully in the home and work environment.

When presenting independent living and homemaking skills instruction to an individual who is deaf-blind, differences and similarities in techniques and strategies used for blindness rehabilitation versus deaf-blind rehabilitation must be considered. Many areas of training

naturally overlap, for example the need for basic organization and labeling techniques.

Adaptive sensory blindness training will focus on sensory deprivation as a result of vision loss and will introduce methodology to overcome the individual nature and degree of this loss. For the individual who is deaf-blind, the hearing loss - essentially how much the person can hear aided and unaided - combined with the vision loss, will impact upon teaching methodology and the successful outcomes of employed practices.

A comparison of strategies used to teach independent living food preparation and cooking skills to persons who are blind versus those who are deaf-blind follows:

SKILL 1.

To ignite the flame of the burner on a gas stove.

Strategy - Blindness: The clicking sound of the flame ignition may be used to

determine when the flame is ignited. Touch clues are used as a safety measure to detect the presence of the flame and to provide additional tactile feedback.

Strategy - Deaf-Blindness: Without auditory input, tactile marks applied to the stove dial and surface are paired to determine the point of ignition. Touch clues are used as a safety measure to detect the presence of the flame and to provide additional tactile feedback.

SKILL 2.

To identify the boiling point of liquids.

Strategy - Blindness: Sound may be used to identify the boiling point of liquids. Rapid boiling liquid emits a fast bubbling sound; simmering liquid a slow or low bubbling sound.

Strategy - Deaf-Blindness: Without the input from sound clues, tactual feedback is gained from vibrations felt through the handle of the pot or from utensils placed within, e.g. a boiling disc, for greater

detection. The emission of steam is also an additional tactal clue.

SKILL 3.

To pour a glass of water.

Strategy - Blindness: Sound changes, from deep to hollow, can be used as an indicator to determine when a glass is full of water. Sound is given off from a liquid level indicator (a gauge with two prongs placed over the rim of the glass) when water touches the base of the indicator.

Strategy - Deaf-Blindness: In the absence of sound clues, the trainee will rely on weight change, temperature change, time element, vibrations felt through a liquid level indicator and tactal feedback using the finger dip method as a guide.

SKILL 4.

To identify heat settings when shallow frying foods

Strategy - Blindness: Sound clues may

be used to determine and to identify the heat setting required when shallow frying foods. When a steady sizzle is heard, the temperature should be lowered. Additionally one can detect the smell of burning or overheating from rising vapors and tactually determine the heat position by selectors on the cooking dial.

Strategy - Deaf-Blindness: When sound clues are not present one can feel the spattering of sizzling fat and the heat intensity of the food vapors. One can also detect the smell of burning or overheating from rising vapors and tactually determine the heat position by selectors on the cooking dial.

SKILL 5.

To determine that the cooking time is complete.

Strategy - Blindness: Small conventional cooking appliances such as a hot beverage maker, toaster oven and microwave oven all emit sound throughout

the cooking process or to indicate that the cooking time is complete.

Strategy - Deaf-Blindness: In the absence of sound clues, vibrations or the lack of vibration are paired with the use of food timers for tactual feedback in addition to that gained from the position of the cooking dials.

Lack of hearing and sight impacts on virtually all daily activities. To meet the challenge of rehabilitation for individuals who are deaf-blind, as separate from those who are blind, the professional must seek to identify tactual clues and adaptive or alternate work methods which compensate for the combined dual sensory loss.

Differences in the Deaf-Blind Population

Individual differences in the deaf-blind population are considerable. The approach to instruction then must take into account:

- The individual in transition from an auditory to a non-auditory functioning

mode.

- The individual in transition from a visual to a tactful functioning mode.
- The individual who is deaf-blind as a result of congenital or other factors that experiences a total dual sensory loss.

A gradual or sudden decline in auditory functioning will decrease environmental awareness through the sense of hearing and will necessitate tactful and sensory skills training to compensate for the loss. For example, one will not hear the sound of an alarm or timer but will need to rely instead on a vibrating alarm to indicate the sound source. Likewise, transition from a visual to a tactful functioning mode implies the use of low vision, strong contrast or color contrast work materials to compensate for the vision loss.

Tactile and low vision training, although beneficial, can be supplemented greatly by the presence of hearing; for example, one may feel the vibration of a

timer but may hear without difficulty with the use of hearing aids in daytime. Unaided and at night, one may require the use of additional tactful information such as a bed vibrator to serve as the wake-up alarm. In the event of a total combined sensory loss, one must rely on vibro-tactile information and any other sensory or environmental stimuli as the information source.

Expectations of the Individual Who is Deaf-Blind

Progress as a result of a rehabilitation program is largely determined by the individual. Motivation, determination and the will to succeed pave the pathway to success. It is important , however, that the expectations of the individual are realistic. They should take into account not only physical, but social, emotional and many times economic, financial and personal adjustment issues. Support from family, friends and service providers play

an integral part in the rehabilitation process. Progress is measured not only through the attainment of clear identifiable goals, but through a sense of personal satisfaction and accomplishment felt at every step of the way.

Expectation of the Rehabilitation Professional

The professional should encourage every individual to set realistic goals, but should guard, nonetheless, against underestimating one's potential; for when expectations are great, greatness will ensue. If a man's time is his greatest asset, (and I believe that it is), then surely the greatest asset of any rehabilitation professional is patience and the ability to define, recognize and reward even the slightest of improvements. The practitioner must guide the person who is deaf-blind to envision a goal, set a course of direction and through rehabilitation, determine the means to success.

Acceptance of the Rehabilitation Process

Many factors contribute to the ability of the individual who is deaf-blind to participate in, to benefit from and to accept the rehabilitation process: fear, confidence, acceptance of tactful methods, the ability to relearn old skills as well as to gain new skills can all be formidable tasks. One may never reach a point of acceptance, yet, if along the journey one can breach small hurdles, an aspired feat can remain a goal, the rehabilitation struggle can be lessened and quality of life can be preserved. If every individual succumbed to occasional feelings of personal inadequacy, pressure or doubt - success indeed would be limited. Moreover then, the need to assist every individual who is deaf-blind through the loop of acceptance - to weigh up the ebb and flow of uncertainty against the greater measure of success.

One can only be effective as a teacher of independent living and homemaking

skills to individuals who are deaf-blind if one understands the complexity of the deaf-blindness and the implications for every individual.

As stated by Mae Lynn Mullen, HKNC student, "Although I learned a lot of skills that I feel I can apply to my life experiences, it is the knowledge and understanding of my deaf-blindness that has given me greater fortitude and acceptance for what lies ahead."

It is the responsibility of the rehabilitation professional to determine strategies, techniques and best practices which will enable the individual to function independently in spite of the dual sensory loss.

Deaf-blindness impacts one's potential for independence with virtually every daily living task. Strategies which consider the nature and extent of both the vision and hearing loss are the most effective rehabilitation practices. Although individual differences are considerable,

techniques can be tailored to every need. Through rehabilitation, acquisition of skills for the homemaker is possible. One may then, if one so desires, become totally integrated to the mainstream of life.



Phine Haugh (R) and former student, Nandani Bhowan.

A STRONG SENSE OF PURPOSE HELPS DEAF-BLIND VENDOR SUCCEED

By Michael Kelley

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Helen Hosse moves along the L-shaped row of vending machines, checking her inventory. Cold drinks, Fritos, chips, peanuts, an array of packaged crackers. Coffee, raspberry shortbread, sandwiches, fried peach pies. "All America loves cookies," she says, so she stocks several kinds.

She checks the change machine, the microwave ovens. "The tricky part is keeping your inventory level to where you've always got what you need but not too much of it," she says. "If you overbuy and it goes out of date, you lose it."

Hosse, who works 7:00 a.m. to 2:00 p.m. Monday through Friday in her canteen in the basement of the Clifford Davis

Federal Building in downtown Memphis, TN, manages all the mundane details of her business - the stocking as well as the bookkeeping. It would be an unremarkable feat except for the fact that her field of vision and her hearing have all but disappeared.

Four years ago, as her sight and hearing declined, she was a volunteer at Interpreting Services for the Deaf and Hearing Impaired at St. Joseph Hospital, billing clients and performing other tasks using a special computer with oversize type.

Yet while the world was fading around her, Hosse, 54, decided that volunteer work wasn't enough. While the temptation was there to roll up into a solitary shell, she decided instead to enroll in the Tennessee Business Enterprises Training Program for the Visually Impaired. She was so successful at it, last year she won the organization's title of Rookie of the Year. And she was named the Quota

Club's District 23 (Tennessee, Arkansas and Northern Mississippi) Deaf Woman of the Year.

Tennessee Business Enterprises is the state version of a program established in 1934, by the federal government to provide employment for the blind and visually impaired on federally owned property. Most participants are blind. Hosse has lost nearly all her hearing as well as vision due to a condition known as Usher syndrome. "She's a good manager," said Mike Rebich, the program's West Tennessee supervisor. "She has overcome a lot of challenges and has really been an inspiration to the program."

"I'm in awe of what she's done," said older sister Alice Lester, a writer and photographer in Houston. "I don't know if I would have had the courage to go like she has."

Hosse, who lives with her husband, Ray, a daughter and a grandson in East Memphis, assumes a matter-of-fact

attitude about her condition. She touches people who come to see her on the arm and explains to them patiently how they can best communicate with her. She reaches for as much independence as she can muster but never tries to hide her impairment.

"The customers and I get along very well," she said. "They're the nicest bunch of people. Sometimes a bag of potato chips won't fall down, or a candy bar won't fall down. If I'm in the storeroom, they'll come get me and take me to the machine, and when I open the machine they'll take my hand and show me what the problem is. They're very accommodating. It's just a matter of people taking a minute to make a little adjustment. And to try to understand."

"I've gone totally blind in the left eye and lost a great deal more in the right eye," she said. "I don't think I'll ever go totally deaf. But the problem is that all my life I've depended on lipreading. Now I'm

having to retrain myself to understand what I hear."

Another problem is that there seems to be little consistency in what she can see and what she can't. "I say that I can't see detail, but when I look at my canned drinks and my bags of chips and things, if I get them in the right light I can read the label. It's really tricky. When I go out to my machines I can read the monitors. I can program them and correct mistakes."

From a drawer in her desk, Hosse produces a slip of paper with the word "fudgesicles" spelled out in braille, with the same word printed in ink below. The label is useful both for herself and the deliveryman.

Hosse was in her 20's and the mother of two children when she learned she eventually would be blind. "We always knew she didn't see quite right," Lester said. "She drove close to the middle line and things of that nature." She had worn a hearing aid since elementary school, but

"she bluffed a lot," her sister said. "Somehow she could pick up on the gist of conversations she really didn't hear. By the time Helen had her children raised and decided she had to do something, she was getting so bad she was losing contact with everybody."

By her own admission, the disease sent Helen into a funk. "I was depressed all the time. I had very little self-esteem. I felt good about doing the volunteer work, but I didn't feel that I had any worth. I felt like I was in everybody's way. I had one great big pity party. And I got tired of it."

Helen recovered by vowing not to allow herself to become isolated. She has succeeded so well she has come into demand as a public speaker. The subject is usually the need for physicians to become more aware of Usher syndrome and the importance of early detection.

"The goal of my speaking is to try to educate anybody who will listen about deaf-blindness," she said. "I'm hoping to

make the way a little easier for the next child who is hearing-impaired and visually impaired."

The frank manner in which she confronts her problems has impressed audiences at various civic organizations. "She doesn't whine. She doesn't say, 'Oh poor me,'" Hosse's sister said. "She just tells it like it is."

"She gave a very moving speech to our group," said Betty Krone, an East Memphis Quota Club member who teaches hearing impaired students at White Station Elementary School. "People were moved and touched and intrigued at what she was able to accomplish, given her circumstances."

Hosse got the idea of going into the vending business from her brother, Richard Harris, a vending machine operator whose hearing and vision losses, also the result of Usher syndrome, are considerably less than her own. "I began to realize I can do more than what I was doing: cleaning

house, taking care of the grandkids," she said. "I asked my brother if he thought I could do what he was doing, and he said, 'Sure. Come up and spend the day with me.' I was hooked after a couple of hours. I knew that was what I wanted to do."

After helping her brother at his business at an Internal Revenue Service facility, she enrolled in the six-week Tennessee Business Enterprises training program and started preparing for her own entry into the entrepreneurial world. "When I started out, there were so many who said, 'She's not going to be able to do that.' They didn't really say that, but I could pick up on their attitudes," she said. "I can't see. I can hear very little. But I can feel people's attitudes. I feel their feelings. And there were so many whose vibes were saying, 'You're not going to make it.'" But Hosse persisted.

"The others were only blind, not hearing-impaired. They had tape recorders. The tape recorders didn't do me

any good," she said. "In class I could not keep up with someone teaching at a rapid pace, so they set up a computer system with a large print program on it and had a typist type everything said in class. I went back to my room, where I had a computer. And that's how I studied. They didn't know if this was going to work, but they didn't know me."

Someday she hopes to progress to a larger, more demanding and more profitable vending operation. She'd like for her husband to be able to retire from his job as a telecommunications engineer and help her run it.

The nine-machine canteen she operates now produces about \$130 a day in revenue. She puts most of the money back into the business, paying herself \$125 a week. "I don't make enough money right now for him to leave his job," she said. "This is my first step up the ladder."

Another goal is to compete some day

for the Quota Club's International Deaf Woman of the Year title. And during Helen Keller Deaf-Blind Awareness Week, she hopes one day to have her picture on the campaign's poster.

ALABAMA FOCUSES ON SERVICES FOR ELDERLY DEAF-BLIND

During a recent visit to Alabama, Martha Bagley, HKNC Older Adult Program coordinator and Susan Brooks, HKNC regional representative, met with Dr. Horace Patterson of the Alabama Institute for the Deaf and Blind. Dr. Patterson is the coordinator of AIDB's new ElderAction Senior Intervention Program.

The mission of the ElderAction Program is to develop a system of service delivery that will ensure that the older sensory impaired Alabamian will be able to maintain a quality of life where he/she can remain functionally independent, be a viable part

of a productive community, and have access to a safe and sustaining environment.

Located within AIDB's Office of Health, Evaluation and Outreach, the ElderAction Program will work to identify older Alabamians with vision and hearing loss, provide training and technical assistance and establish a service delivery model. Services developed under this program will directly address the needs of older adults who are deaf-blind and who are vision and hearing impaired.

Dr. Patterson has prepared a comprehensive overview of the older, sensory impaired population within Alabama. Within that document, Dr. Patterson asserts that "60 (years) is a mid-point, not an end point." His statement rings true as all Americans are living longer and demanding that those later years be worth living.

Dr. Patterson is uniquely qualified to create the ElderAction Program. He is a

former director of Talladega County's Retired Senior Volunteer Program (RSVP) and he is also the pastor of the Mt. Canaan Baptist Church in Talladega.

HKNC applauds Dr. Patterson's work at AIDB, the Alabama Commission on Aging and the Alabama Division of Rehabilitation Services for their continuing commitment to meeting the needs of older adults who are deaf-blind. AIDB's ElderAction Senior Intervention Program along with Alabama DVR's Independent Living for Older Blind Program (OASIS) have the potential to provide a unique network of services for older adults with hearing and vision loss in Alabama.



(Left to right) Martha Bagley, Dr. Patterson and Susan Brooks.

INDEPENDENT LIVING STILL POSSIBLE WITH DISABILITIES

by Tanya Ho, Staff Reporter
(Reprinted from the Toronto Star,
Toronto, Canada)

Nazar Strejko is deaf and blind, but he refuses to let his disabilities hold him back in any aspect of his life. The 55-year old has flown a small plane with the help of a pilot sitting next to him. An instructor signals him where to steer his boat with a tap on the shoulder. And for skiing, he wears special equipment controlled by an instructor who helps him change directions or stop. Now he's learning braille.

Strejko is also an optimistic advocate for Helen Keller Deaf-Blind Awareness Week which is held every year in June. "When you go to bed with a disability, it's hard whatever you do. But I don't worry; I like to have fun," he said.

Strejko credits the staff at Rotary Cheshire Apartments, a low-rise in North

York that houses 15 other deaf-blind adults, for his happiness and independence. The complex was established by the Toronto Don Valley Rotary Club in 1992. A variety of programs help promote independent living for residents, including social and recreational outings, moral support and intervention services.

Strejko now sees and hears a world of difference. Every day he has four hours with an intervenor who helps him communicate through tactile finger-spelling. Each letter of the alphabet is designated a spot on the "reader's" hand. In this way, the intervenor is able to spell out sentences to help Strejko relate to the world around him.

During the 16 years Strejko lived in a high-rise at High Park Ave. and Bloor St. W., he worked six hours a week with an intervenor. "I lived on the 20th floor of a 25-floor building. Many people were around, but I had nobody," Strejko said. "I

can do so much more since I've had a lot of help."

"I really respect his level of independence and his sense of humor," said Cheryl Laliberte, an intervenor who has worked with Strejko for five years. "He has a lot of character; he's always really full of ideas. For a lot of tenants, we suggest things to do. With Nazar, he's got his plans all set up. There's never going to be a dull moment with him. He doesn't let his disability get in his way."

Strejko represents his fellow tenants on the board of directors at the Rotary Cheshire Apartments. He is also a member of the Deaf-Blind Association of Toronto. And he's worked at the Canadian National Institute For the Blind for the past 23 years.

Strejko began to lose his sight and hearing when he was only four and living in Poland. At 23, he came to Canada and taught himself English using a dictionary. But by 1979, he couldn't see well enough

to read books. Until a year ago he still had partial vision. Today, he can only distinguish between light and dark. "Before, when I could see, I had many friends. When I lost my vision, they left. It is a sad fact," said Strejko.

But he is still very positive about his life. "I live from day to day. I would like to help other people who are more disabled. Other people do that for me."

EDITORIAL NOTE: The Rotary Cheshire Apartment for the Deaf-Blind described in the preceding article is unique. By all accounts it is the best planned environmental setting for deaf-blind individuals who yearn for independent living and freedom to express themselves socially as individual personalities. This year the Rotary Cheshire Apartments celebrated its fifth anniversary.)

ELVA

(Reprinted from the Rose Resnick Lighthouse for the Blind and Visually Impaired Annual Report, 1996, San Francisco, CA)



Elva is a model student at the Rose Resnick Lighthouse for the Blind and Visually Impaired in San Francisco, California. She is bright, talented and enthusiastic. A quick learner, she knows exactly what she wants to do and how she wants to do it. Clients and staff love her personality and her sense of humor.

Elva has been deaf since infancy and experiencing progressive vision loss for thirty years, receiving comprehensive services from the Lighthouse only since

early 1996. Starting with indoor orientation and mobility training, she is now learning braille and keyboarding, as well as taking a ceramics class; she will begin learning sign language in the near future. Until two years ago, Elva had some misgivings about what a services agency like the Lighthouse could offer her.

According to Elva's daughter, Elva's mother wanted Elva's interactions and experiences to be as "normal" as possible but was not familiar with the resources available to people with disabilities. After her grandmother's death, Elva's daughter brought Elva to the Lighthouse, hoping to provide her with new skills and some social interaction to help make her life fuller and more independent. "It took my sister and me a good six months to convince my mom there were other options," said Christina McNare, Elva's daughter. "She thought she had a good life."

The staff met with Frank Lester, the Lighthouse's coordinator of Deaf-Blind

Services, to address Elva's needs. Communication was the major concern. Elva's own system of communication - using her fingers to print letters in the palm of her hand is, without practice, a bit cumbersome. Those who have worked with her have become fairly adept both at print on palm and in understanding Elva's speech.

Having some experience in working with clay, it was decided that Elva would start out in the arts and crafts room, taking a class with Patrick Farley. This was to present her with an initial experience which was sure to be positive, give her some confidence and allow staff to observe how she managed social situations. "Elva is quite precise about what she wants to do, what tools she wants to use; she is very adept with clay," Patrick noted.

Since beginning ceramics classes in February 1996, Elva has made several bowls on the potter's wheel and has spent six months perfecting a ceramic duck. "We

think maybe she's satisfied, then the next week Elva comes in, rips it apart and starts all over. She's quite a perfectionist," Patrick said.

A perfectionist and a quick learner is the consensus of Lighthouse staffers who have worked with her. Elva began learning braille at about the same time she began ceramics classes and she has already mastered the entire alphabet, as well as most of Grade II, which consists of other braille signs and contractions.

In May of last year, she began learning the typing keyboard from Dawn Atienza, the Lighthouse's rehabilitation skills teacher. "Elva doesn't really need me anymore, which is sad because I enjoy her company. She's bright and very, very funny," Dawn said. "I thought communication would be a huge challenge, now we spend most of the lesson just talking."

The reason behind teaching Elva to type was so that she might use the TeleBraille

to speak to her daughters over the phone. Elva's daughter Christina said this is a meaningful change in her relationship with her mom. "We can talk to her whenever, without inconveniencing someone else - just to talk to her whenever about anything. It is just so moving," she says.

Now that Elva has the basics down, she would like to take a cooking class and go bowling with some of the other Lighthouse clients. It's a far cry from even one year ago. "Our initial deal was I would go with her to two of each of the classes she was taking, she didn't want to go alone," Christina remembered. "Now she's wishing there were more opportunities to socialize!"

READER'S FORUM

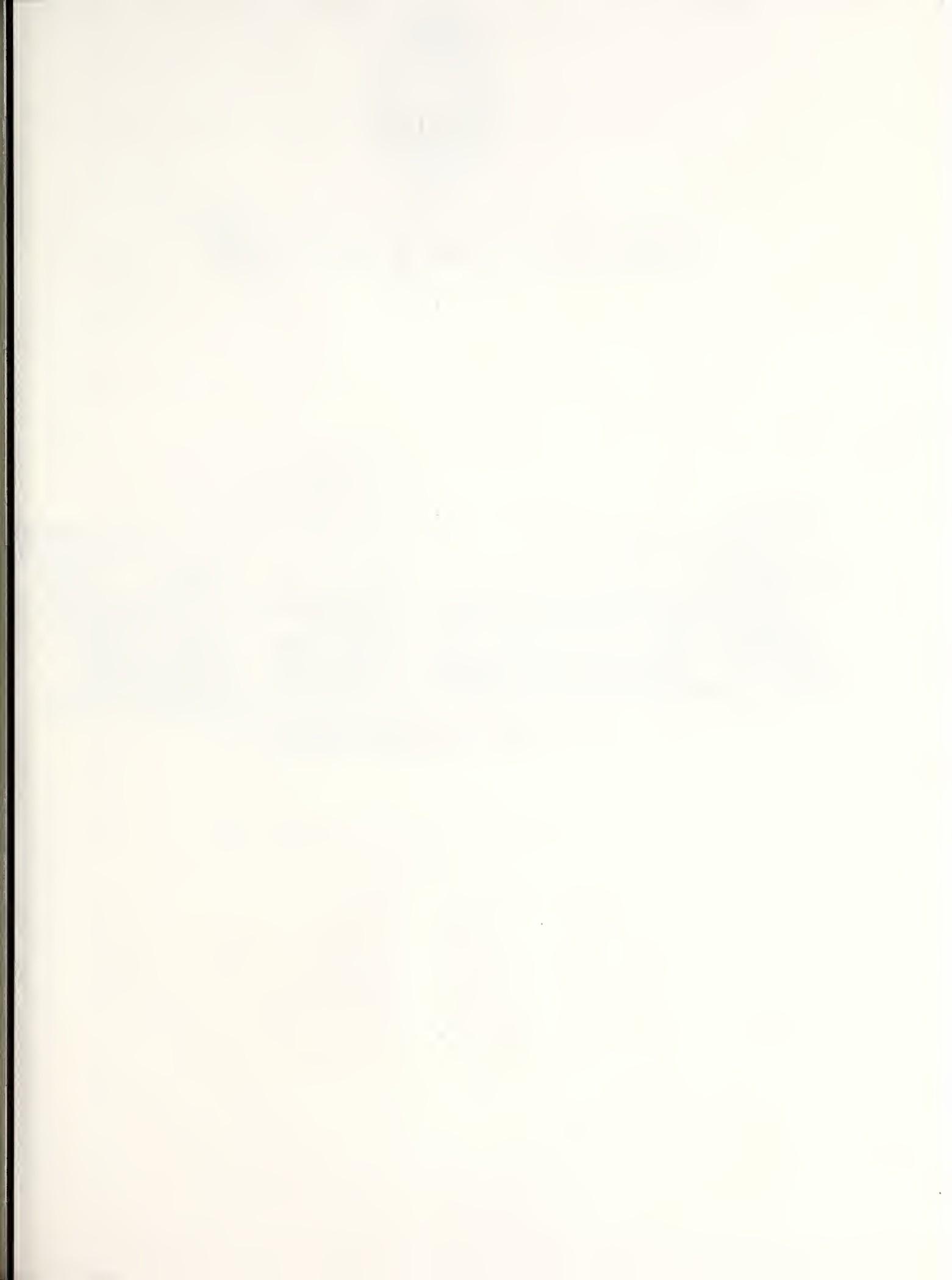
From Bryan Satler, New York

The following information is for your READERS' FORUM in NAT-CENT NEWS:

1. One needs to be completely organized and not allow sighted persons to constantly move objects on you.
2. I recommend for mobility that you use a guide dog and that you use sighted assistance to cross streets.
3. Use writing guides.
4. Get programmable hearing aids and a FM system, if you have any usable hearing left.
5. Besides using the FM system to talk and listen to someone in large group, you should use it to listen to TV, radio, tape player and any other audio device. This will keep noise level down for other persons.
6. If possible, use braille tags on clothes.

7. Pin socks together to keep them sorted.
8. Use High Mark when necessary.
9. I am a firm believer is using total communications and total mobility skills.

Thank you for reading these suggestions.



NAT-CENT NEWS

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FOR DEAF-BLIND
YOUTHS AND ADULTS
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Sands Point, NY 11050

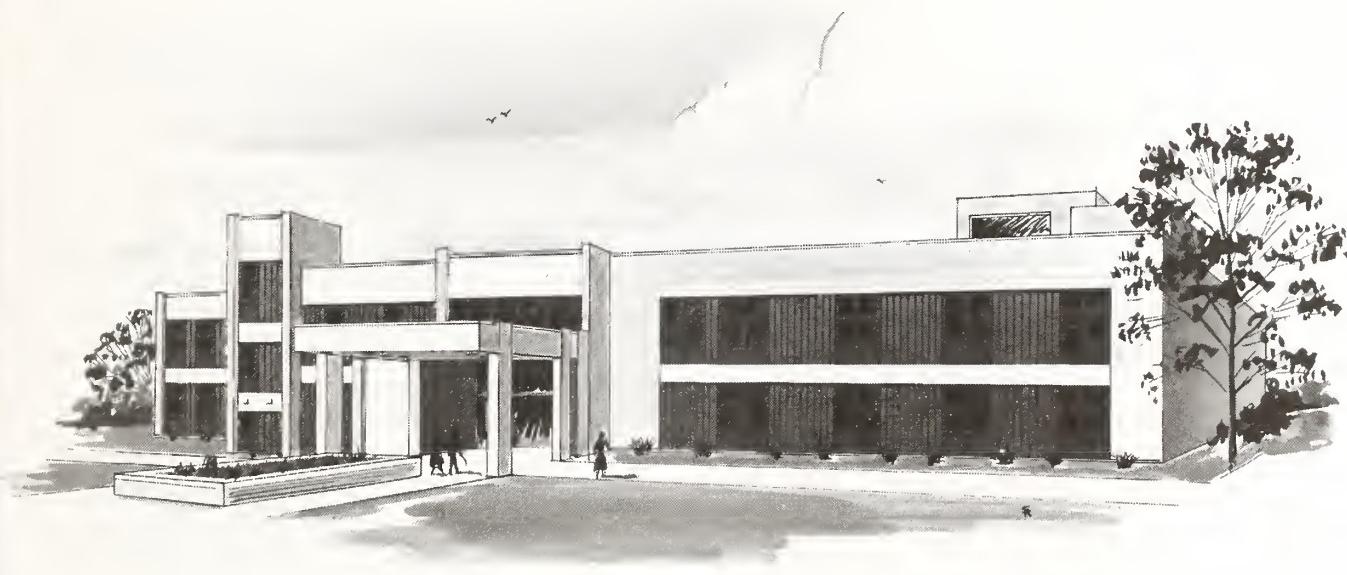
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ASSOC. EXECU. DIR. PROG. SVCS.
AMERICAN FOUNDATION F/T BLIND
11 PENN PLAZA SUITE 300
NEW YORK, NY 10001



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EDITOR — ROBERT J. SMITHDAS, L.H.D., Litt. D., L.H.D.

Editorial Assistant — Allison Burrows

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EDITORIAL: AN INTERNATIONAL GUIDE

By Robert J. Smithdas, LHD, Litt.D., LHD

Recently I received a large padded envelope from the Royal National Institute for the Blind in London, England. It contained a large, magazine-style book which I learned, after showing it to my secretary, was a copy of "Equipment for the Blind and Partially Sighted Persons - An International Guide." Checking further, I was delighted to learn that it contained a special section on aids and devices for deaf-blind individuals as well.

This guide was compiled by Dr. John Gill, research scientist at the Royal National Institute for the Blind in Great Britain, with whom I have been in contact for several years. The guide is a comprehensive source of producers and products from many countries, providing information consisting of a description of each product, its use, price, and technical details. Also included are addresses and telephone and fax numbers for sources of supply. The guide

covers a range of categories, each with a wide variety of items. To my knowledge, this is the most comprehensive listing of aids and devices available.

Of special interest to this writer is the section of the guide devoted to aids and devices for use by deaf-blind people. Dr. Gill had sent me previous lists of items useful to the deaf-blind, and I was fascinated by the variety of signalling systems, clocks, communication aids and other devices available from countries such as Norway, Sweden, Germany, France and even Switzerland. Obviously, there is much to choose from and it is unfortunate that the current catalogue is not available in braille.

Most of the devices from Europe use 220-volt electric power to operate, which may seem a critical drawback for use here in the United States unless one remembers that there are converters that can easily be purchased so that they can be used with domestic power standards.

If readers are interested in obtaining copies of the new "Equipment Book for Blind and

Partially Sighted Persons," inquiries should be sent to Dr. John Gill, Research Scientist, Royal National Institute for the Blind, 224 Great Portland Street, London W1N 6AA, England UK. Telephone 071-388-1266.

RICHARD RAMM: ENTREPRENEUR AND AUTHOR

By Jessica Kowal (Reprinted
from NY NEWSDAY)

As his vision and hearing slipped away, Richard Ramm brought his daughter to business meetings to sign others' words into his open hand. In his 50's, though disabled, Mr. Ramm wrote books on betting strategies for blackjack and baccarat. In his 60's, blind and deaf, he learned to read braille.

Mr. Ramm died November 18 of congestive heart failure at Beach Terrace Nursing Home in Long Beach, NY. He was 73.

"By virtue of his disability, the theme throughout his life was really one of loneliness

and isolation," said daughter, Carolyn Thornlow, of Hastings-on-Hudson, NY. "And that's probably what drove him to be involved with people."

Born April 6, 1924, to Louis and Bertha Ramm, Mr. Ramm grew up in Brooklyn and attended Riverside Military Academy in Georgia through high school. Mr. Ramm had Usher syndrome, a hereditary disease combining deafness with eventual blindness.

Mr. Ramm studied chemical engineering at New York University and received a master's degree in the same subject from the Carnegie Institute of Technology in Pittsburgh.

In the late 1940's, at a weekly meeting at the Lighthouse, a Queens-based organization that provides services for the blind and visually impaired, Mr. Ramm met Jean Bogert, a volunteer. They married on May 6, 1950, and lived in Forest Hills, NY, for a few years before moving to Levittown on Long Island.

Working out of home, Mr. Ramm became a stock broker and made a small fortune in the 1960's and then decided to purchase franchise

businesses. Mr. Ramm opened Insty-Prints stores in Levittown, Floral Park, Melville and Riverhead, and also owned Connoisseur Wines and Spirits and Gift Shop in Westbury, the Vintage House Restaurant in Deer Park and Poor Richard's Inn in Lake Ronkonkoma. He later sold the businesses and learned computer programming, which led to a new career as a book author, collaborating with Henry Tamburin on two books about the mathematics of casino gambling.

In his early 60's, his hearing and vision gone, Mr. Ramm learned braille at the Helen Keller National Center in Sands Point. He also wrote a computer program to translate closed-captioned signals on television into braille so he could keep up with news shows.

In addition to his wife and daughter, Mr. Ramm is survived by a sister, Irma Rosenberg of Montclair, NJ, and a granddaughter, Johanna of Hastings-on-Hudson.

Editor's Note: Your editor had the privilege and pleasure of becoming acquainted with

Richard Ramm while he was a student at HKNC. We became good friends and Richard would often stop in to visit with me after he finished his training at the Center. He possessed a brilliant, unusually perceptive mind, endowed with exceptional intelligence, always courteous and infinitely patient. (My wife, Michelle, who taught him braille, was also very fond of him.) He was a gentle, considerate man of exceptional talent.

FORMER HKNC STUDENT WINS AWARD

Joseph Ciancaglini, from Voorhees, NJ, was recently awarded the Employment/Education Award from the New Jersey Association for the Deaf-Blind (NJADB). Joe, who was "in a sense, a normal person" until age 35, became visually and hearing impaired at age 36.

The Employment/Education Award is given by NJADB to an individual who has demonstrated significant improvement in the

areas of employment and/or education within the past year. This may include: successful employment, improved work/school behavior, increased production and improved grades.

Linda Wilson, Assistant Executive Director of NJADB, presented Joe with the award and said: "Over the past year, Joe has shown great improvement. He has begun sign language instruction to improve his signing skills so that he can communicate with other people who are deaf. He practices his signing skills with others. He converses with NJADB staff and peers and if he doesn't know a sign, he will ask for the right hand movements.

"Joe also has been working with the Commission for the Blind to improve his employment skills so he can return to work. He was enrolled in the Business Enterprise Program to learn managing and supervisory skills, running a business, customer relations, codes and violations that are involved with running a business. He completed this program in July, 1997, and will be set up with his own business upon availability of vendors supplied by the

Commission.

"Joe advocated successfully for himself during the sale of his home - negotiating with real estate agents and attorneys."

"I was in a small state of shock," said Joe. "Without the help of the Helen Keller National Center, the Commission for the Blind and the NJADB, I would never have gotten this far."

**OUT OF HIS SHELL.
DEAF-BLIND STUDENT LEAVES
SCHOOL OF HARD KNOCKS**
by Katie Thomas (Reprinted from
NY Newsday)



Scott Stoffel could be hard to spot in a crowd of fellow Hofstra University students. A computer science and creative writing major, the handsome redhead juggles a full load of classes, a part-time job, and still finds time to fiddle with his third novel. Stoffel and his wife, Sandy,

share a small on-campus apartment, and often stay up late at night worrying about how they'll pay bills.

He's a typical college student, save one detail - Stoffel, 29, is legally blind, deaf and has almost no feeling in his fingertips.

Doctors who examined him and his similarly afflicted older sister, Gretchen, say the cause of their unnamed disorder is a mystery. Despite the severity of this disability - Stoffel's condition prevents him even from reading braille - he has managed to earn a 3.85 grade point average at Hempstead's Hofstra University in Hempstead, NY, write his unpublished novels, compose volumes of poetry and invent a computer program that helps him study.

Today, Stoffel, who had his hearing until he was 18 and relies on his memory to speak in a normal voice, jokes about his wife's knack for making money disappear, and he frets about serious, yet common, challenges such as paying college tuition. He's struggling now, but getting here was even harder.

Stoffel, a military brat whose parents moved

around a lot, was born legally blind. He can see shadows but not recognize faces, and can read print on a computer screen if it is no more than 4 inches from his face. His sister, Gretchen, 35, is also legally blind and lost her hearing when she was 8. Dr. John Friedman, the neurologist at Baltimore's Johns Hopkins University who examined Stoffel and his sister when Stoffel was a young boy, says the cause of their disorder is unknown.

"It is unique," Friedman said, adding that when he diagnosed the siblings in 1975, doctors searched for a patient with similar symptoms but found none.

Growing up blind, Stoffel learned to compensate for his disability with talking books and tutors to earn passing grades in school. But just after he graduated from high school in West Simsbury, Connecticut, Stoffel lost what he saw as his only link to the outside world - his hearing.

In a period of three months, Stoffel lost his ability to discern speech, preventing him from continuing as an assistant manager at a computer

store in Chattanooga, Tennessee. Frustrated, Stoffel returned home to Connecticut. "There was nothing left for me to do socially," he said. "I became a very angry, bitter person for a long time."

Isolating himself even from his parents, Stoffel kept busy by writing. His first science fiction novel - typed out on a computer and read using a magnifying glass to see the screen - took him four years to write. But Stoffel's depression worsened, and as years passed, he started abusing alcohol and over-the-counter pain killers.

"I was getting crazy," Stoffel said. Finally, he realized that "I didn't have any kind of a life. I wanted to learn how to do things with my life."

One of his former tutors told him about the Helen Keller National Center, which teaches deaf-blind students like Scott tactile sign language. To listen, Stoffel rests his hand on that of the person signing and "reads" the changing shape of the speaker's hand as language. After some initial resistance - "I

didn't want to be classified as one of the students," Stoffel said - he enrolled at the Center in 1994.

With the help of a few friends at the Center and his journal, Scott slowly began to come out of his shell. One of those friends, Sandy Lamb, a 39-year-old woman with Usher syndrome, a condition that causes hearing loss and gradual blindness, also helped Scott emerge from his depression. "It was love at first sight," Sandy said. "Or should I say touch?" The two military brats, who met through a mutual friend at the Center, quickly became best friends and were married last year.

Gradually, as he became more proficient in tactile sign language, Stoffel began to think about college. While at the Center, he taught himself computer BASIC language and developed a program called "Eye-See Braille Reader," which translates text on disk into a large, pictorial version of braille. Each letter flashed on the screen in braille format, allows Stoffel to read text on the computer without straining his eyes.

In the fall of 1995, Stoffel began classes at Hofstra University. Through its University Without Walls Program for Disabled Students, the school provides him with sign language interpreters for regular classes, and also allows him to take classes with professors one-on-one.

Since last semester, Stoffel has been taking a full load of classes, and also spends two days a week as an assistant technology instructor at the Center. He is now trying to finish his latest fantasy novel, as yet untitled. When he gets a few spare minutes, Stoffel practices new rope, card or mind tricks on his wife and he has recently learned to read Tarot cards.

Like many college students, Stoffel relies on grants, an academic scholarship from Hofstra, his part-time salary and loans to cover the bills. But he still hopes he'll be able to continue his studies. The copyright for Stoffel's braille program was just approved, and he said he's going to try to market it to software companies.

Barbara Hausman, a spokeswoman for the Center, which has been trying to raise money for his tuition, said Stoffel and his wife have

been through worse. "He's so brilliant and has such good potential," she said. "They've overcome tremendous odds already and they will continue to struggle."

CORRECTION

In the September, 1996, issue of NAT-CENT NEWS, an error was made in the zip code for Blindsights, publisher of DIALOGUE magazine for the blind. To order a year's subscription to the magazine, send your request and check to Blindsights, Inc., P.O. Box 5181, Salem OR 97304-0181.

DIALOGUE is truly a special magazine for blind and deaf-blind readers. It is entertaining and informative. No other currently existing magazine provides such a wide variety of articles of interest for readers who are blind or visually impaired - giving up-to-date information on useful products and aids, as well as happenings in the field of rehabilitation.

AUTUMN

By HKNC student, Celine Bush

The autumn days are growing short
And nights come crisp and cold.
And soon the leaves so bright and green
Will be colored red and gold.

And autumn apples, firm and fresh
Will make their way to pie,
And perched on sticks, and candy-wrapped
Indeed, you'll want to try!

And apple butter sauce and cake
What else is there to say?
Oh, yes, and eat them as they are
To keep the doc away.

And soon our feathered friends will fly
To new homes far away,
But they'll return in early spring
To brighten each new day.

TRAGEDY AND TRIUMPH

By Carrie Spencer. (Reprinted from The Saganaw News, Saganaw, MI)

Editor's Note: NAT-CENT NEWS carried an article about Michael Stutelberg in its September, 1997 issue. We are reprinting the following story because it provides a more detailed and graphic insight into Michael's problems and his efforts to overcome a difficult personal tragedy.

Michael Stutelberg often asks the same question of the support staff in his assisted-living home in Midland, Michigan. "He says, 'Isn't this housing for people with disabilities?'" said Teresa Huff, his job coach and one of the support workers from Arc of Midland. "He asks, 'What's my disability?'"

The 20-year-old can't see, is nearly deaf and has limited sense of touch. But family and therapists who worked with him at the Helen Keller National Center (HKNC) from September 1995, to August 1996, have helped him in his

determination to live as independently as he can. He shops for groceries, works at a sporting goods store and is an avid sports fan - make that a fanatic! "I need to work because I don't want to sit around all the time," Stutelberg said. "And I need to make money."

A rare genetic disorder that affects mitochondria, tiny cell structures that provide all the body's energy, struck the bright and athletic teenager five years ago. He is the second person with the disease to train at HKNC said Suzanne Ressa, his case manager.

Congress established the Center in Sands Point, NY, just outside New York City in 1969 to train people who are both blind and deaf to live independently. Keller, a longtime advocate for rights of people with disabilities, had died the year before.

"The government wants people off of social security and actually contributing back to that (system)," Ressa said. "The only way you can contribute is by being employed. It also sends a message to the community, to help people living with disabilities. It says to children, I

don't have to be afraid of somebody who's disabled. It's just part of the norm."

Therapists and his parents, Greg and Mary Stutelberg of Midland, say Mike Stutelberg has never succumbed to self-pity. "He always feels sorry for the other guy," said his mother. "When Kirby Puckett had to quit baseball because of his vision, Mike was just devastated. One day, he just said to me, 'Aren't you glad I got used to being blind?'"

Last year, Michigan schools reported 293 students who are both blind and deaf, according to the Lansing-based Deaf-Blind Unit of the Michigan Commission for the Blind. The measure is imprecise, because some students are misclassified, lead worker Cynthia Caldwell noted. Still, it's the only attempt to keep any statistics. The vocational and rehabilitation service can't keep track of adults unless they seek services, she said.

The best guess is that 800 to 1,000 state residents have impairments to both senses. Lack of data hampers efforts to attract research funding, she said. Last year, 10 people from

the six-state midwestern region went for training at HKNC.

With 24-hour staff on hand, Stutelberg and a roommate now live in a three-bedroom ranch. "I can get around my house pretty well now, but when I first got here, I didn't understand how to get from place to place," he said. I'm getting better each day."

Huff also accompanies Stutelberg to his job at Dunham's Sporting Goods in Midland, where he prices items and stocks shelves. Huff guards against mistakes and guides him through the aisles.

HKNC trainers prepared him for his return to work. "There were sports he didn't know anything about," Ressa said. "He didn't know what a lacrosse helmet looked like. He had to learn about a sport he had never seen - never had an opportunity to learn anything about."

Because the illness also brings memory loss, when therapists placed a football kickoff tee in his hands he couldn't tell what it was. "If we gave you that item and you were blindfolded (and had never seen one), would you be able to

guess what it is?" Ressa said. "Mike's memory is based on a tactical memory instead of a visual memory."

When he was a freshman at Midland Dow High School, Stutelberg had his first stroke, which impaired his peripheral vision. Doctors diagnosed a type of mitochondria disease called MELAS syndrome, which involves falling energy production in the brain, leading to strokelike episodes.

People with the disease no longer retain visual memories, noted Dr. Kenneth J. Gaines, chief of neurology at the Field Neurosciences Institute at St. Mary's Medical Center. "That area of the brain is more than processing the light impulse; it interprets what you see," he said.

Four months later, at age 16, a second stroke took his vision. When asked what his life was like before the illness, Stutelberg said he couldn't remember. He paused, then laughed and added: "Oh yeah, the Vikings were playing the Giants in the playoffs and I couldn't watch it."

Other symptoms can include short stature, headaches, memory loss or paralysis on just one side of the body. Staff at HKNC had to prepare him for eventual deafness by teaching him sign language.

Because his sense of touch is impaired, he can't use the traditional method of feeling the sign the other person's hand is making. Instead, he has to rely on his own sense of body position - the speaker molds Stutelberg's hand into the sign for a letter or word, and he says it aloud to indicate he understands. "We taught the family the same technique," Ressa said.

Last December, Stutelberg lost the rest of his hearing. However, he is the first person with his disease to successfully receive a cochlear implant. Hearing aids just amplify. The implants do the job of the damaged inner ear, directly stimulating the hearing centers in the brain. "He can hear far better than we ever anticipated," Mary Stutelberg said.

"When he was cut off, he went into sensory deprivation. He was in his own little world. We couldn't get through to him. You'd hit him,

you'd pinch him. He would just be laughing constantly and talking. Everything he was talking about was stuff that happened, but we couldn't bring him back to reality." That's when the family decided to get the implants to ensure that some stimuli could get through.

Milton Warren, 70, who volunteers four to five days a week at HKNC, still misses his favorite client. "I have had many students, but when Mike came in we just hit it off more than I had with anyone else," Warren said. "I would bring a newspaper every day and we'd go over whatever (sports) season it was. I tried to get him to do other things, but it seems he would always come back to what was going on in the world of sports."

Stutelberg took frequent walks with "Uncle Milty," who invited him to his Manhasset, NY, home before he left. "We talked about the future, and we talked about girls," Warren said. "He'd say, 'I don't know if I'm ready to get married yet.' He was a terrific kid to be with because his outlook was as if nothing had ever happened to him."

Family and support workers are trying to work out a system so Stutelberg can talk on the phone, Warren said. "The conversation will probably be: 'Where is the dollar you owe me?' We bet on a game and he reneged on me. He'd say, 'Oh, I don't have change on me.'"

READERS' FORUM

From: Bryan Satler, Schenectady, NY:

A Computer makes an excellent tool for communications. It can be used to write, and also to read print.

I think the specifications for a computer useful for deaf-blind individuals should be:



1. A pentium computer operating at 133 MHZ
2. 1 GB of hard drive
3. 256 KB of cache; and
4. 8 MB of RAM.

If you plan to use the computer for accessing the Internet, then a 28,000 VPS modem would be best. If you have useful residual vision, it would be best to use the largest color monitor you can afford.

There are three common ways to access a computer: by using a magnifying screen, a speech synthesizer, or a refreshable braille display. Your choice will depend upon the degree of your visual and hearing loss and also on how deep your pockets are - equipment can be costly! Screen magnification is cheapest; refreshable braille displays are expensive.

I am blind and have some usable hearing, and since I can't use braille, I use a speech synthesizer. I use a BEC-Talk speech card and ASAP screen reader. I use Word Perfect to write, and an Arkenstone Open Book scanner to read printed materials.

Yes, computers and access equipment are costly, but there are sources of financial aid available, and your local rehabilitation agency may prescribe assistive equipment for you.

MAN WHO KNEW NO BOUNDS

By Matthew Ebnet (Reprinted from The
KANSAS CITY STAR, Kansas City, Mo.)

Throughout Leonard Dowdy, Jr.'s life, folks asked the same, naive questions over and over. Why go out? Why travel? Why have a rose garden? You can't see, they said, you can't hear, so why? They weren't being cruel; they simply didn't understand.

Because, in many ways, Dowdy could see and hear with the tender, sensitive tips of his fingers. Over the course of his life, and all over the United States, Europe, South America and the Caribbean, Dowdy skirted the blackness and silence that filled his head and felt his way around the outside world. And, in the end, figures his sister, Louise, "he saw things more clearly than we do."

Dowdy, who has been written about many times in national magazines and in "The Star," died of pneumonia this past September at the Johnson County Nursing Center in Olathe, KS. Dowdy, who as a baby contracted spinal

meningitis that left him blind and deaf, was 70. He is survived by his wife, Betty, who is also blind and deaf, his sister and two brothers.

Dowdy has left a bigger legacy than even he might have expected, his friends and relatives say. In the '70s, Dowdy's former teacher wrote a book about his life, "The Story of Leonard Dowdy." He has won awards from deaf-blind advocacy groups. But it was a vigorous determination - he built his own workshop - that aroused countless deaf and blind people, and even those who could see and hear, to be more self-sufficient, those who knew him say.

"He knew no bounds," said Lester Kahn, Dowdy's brother-in-law. "He's blind and deaf. He would saw on power saws." Using a rope, Kahn said, Dowdy "cut the grass by putting a stake in the middle of the lawn and mowing in circles that got smaller and smaller."

Ken Stuckey, a librarian at Dowdy's childhood school, the Perkins School for the Blind in Watertown, MA, said, "He's a tremendous example for everybody. He wanted to know the name of everyone and everything

he touched."

Dowdy became one of only a handful of people in the world - one of only about 20 in the United States - who could place his hand over a person's throat and lips and "hear" by feeling the delicate vibrations of a person's vocal cords. This method, called Tadoma, is considered excruciatingly difficult, if not impossible, for most to master.

Dowdy was carefully studied by scientists, most notably at the Massachusetts Institute of Technology, who wanted to figure out just how he did what he did. If he hadn't fallen sick, relatives said, he would have traveled to Norway with two MIT scientists to do more research.

"He transcended handicaps," Stuckey said, "and wanted to help others do that, too." In fact, to the surprise and disappointment of some of his relatives, Dowdy's last wish was to donate his body for doctors to study.

COMPUTERS TO HELP PEOPLE, INC. INTRODUCES ITS TECHNICAL BRAILLE CENTER

by John J. Boyer, Executive Director

Editor's Note: This editor has had the pleasure and privilege of knowing John Boyer for many years. John is a man who, despite the loss of sight and hearing since he was a youth, has accepted the challenges of life and accomplished unusual success in establishing Computers to Help People, Inc., a small agency in Madison, Wisconsin. Brilliant in mathematics, he has a master's degree in computer science and once trained his own guide dog! In this article he introduces his newest venture, the Technical Braille Center.

What's the Technical Braille Center?

The Technical Braille Center (TBC) produces highly technical books (containing lots of math), journals, reference materials, etc., for people who cannot use ordinary print. The chief formats are braille, large print, and

various types of electronic files. The word "braille" is used in its name because braille is the prototypical special medium. The Center operates as a unit of Computers to Help People, Inc. (CHPI). This is a nonprofit organization. This type of braille is preferred by most blind people and it will also save money on paper and shipping.

Aren't people already doing things like this?

Yes, but not nearly enough. Current methods are too slow, expensive time-consuming, and can satisfy only a tiny fraction of the demand.

Why will the Center do a better job of satisfying the demand?

The Center capitalizes on recent advances in the computer field, notably in braille translation software. We use MegaDots, the most sophisticated braille translation program in the world. The Center is run by the developer of the mathematics features of MegaDots. He is himself deaf-blind and has struggled all his life

to obtain highly technical material. He founded CHPI 16 years ago and has the advice of other successful businessmen on the Board of Directors.

Who needs it?

Working blind scientists, engineers, computer programmers, electronics technicians and mathematicians. Students studying for these and similar careers. People with dyslexia or paralysis.

How much good will it do?

By a conservative estimate, there are over ten thousand print-handicapped professionals in the United States. Then there are the students who are preparing for careers in the technical professions. Last but not least, there are countless students who are discouraged from such careers by the lack of technical material in suitable media. For all of these people, the Center will greatly further their careers and studies.

Why can't they just use tapes?

Their non-handicapped peers don't and wouldn't consider tapes adequate. Only a written medium such as braille can do a satisfactory job of conveying mathematics.

Why should CHPI run it?

CHPI has 16 years of experience in applying computer technology to the problems of people with disabilities. The director of the Center (and executive director of CHPI) is himself deaf-blind and has struggled all his life to obtain the technical material which he needs as a computer scientist and mathematician. He therefore knows all too well what potential clients of the Center face and is highly motivated to make it a success. As the developer of the mathematical translation features of MegaDots, he is in the best possible position to deal with problems as they arise. CHPI has a close relationship with the vendor of MegaDots and can therefore get glitches in other parts of the software attended to quickly.

How will it be funded?

The Center seeks to earn as much of its funds as possible through the sale of books in various formats. We are working on a proposal for a large grant which will finance a five-year plan. But in the present proposal we are just asking for booster money to help us get off the ground.

What will you use the money for?

Six thousand dollars will go for paying students from the University and colleges in this area to edit the books after they have been scanned into the computer. We just don't have the money to do this. But once we can start doing it, the operation will be self-supporting. Four thousand dollars will be used to purchase a modern braille printer which prints on both sides of the page. This type of braille is preferred by most blind people, and it will also save money on paper and shipping.

For further information, contact: John J. Boyer, Executive Director, Computers To Help People, Inc., 825 E. Johnson Street, Madison,

WI 53703; (608) 257-5917 (Voice and TTY);
(608) 257-3480 (FAX).

MISSION POSSIBLE

(Reprinted with permission from
The Cochlear Corporation)

Paralympic medalist, Kathy Urschel, age 33, would have given up when she became blind 11 years ago and then deaf six years later. Instead, the Baldwinsville, New York, woman earned a master's degree, became a youth counselor and entered the wide world of sports as a tandem cyclist.

"Anything is possible. It's just a matter of how badly you want something, and how hard you are willing to work for it," says Urschel. And she is more than willing to work hard.

In fact, determination and spunk are Kathy Urschel's middle names. With the help of a Nucleus cochlear implant - a surgically implanted device that bypasses damaged nerve fibers enabling severe-to-profoundly deaf people

to hear sounds and understand speech - Kathy works with kids over the phone and in person, gives motivational speeches at school assemblies and organizes community events. She also competes in tandem cycling events around the country. Last year, Kathy won the silver medal in the 1996 Paralympics. More recently, she became the first disabled female to complete in the 3,050 mile Race Across America (RAAM).



"None of this would be possible without my cochlear implant," says Kathy. "It helps me with everyday life and enables me to follow my

dreams."

Now focusing on the 2000 Paralympics in Australia, Kathy is once again rising to a challenge that not many people could meet. In between training sessions, she will continue to use her personal experiences to help kids in her community set and meet their own goals. Explains Kathy, "We all have been put on this earth with the opportunity to make a difference. No self-expression is neither too great nor too small as long as we feel a sense of accomplishment."

For more information on cochlear implant technology, call the Cochlear Implant Information Hotline, 1-800-458-4999 (voice), 1-800-483-3123 (TTY), or Cochlear Corporation's website www.cochlear.com.

SCORE PUTS ITS WISDOM TO WORK

By Jerry Ackerman (Reprinted from the
BOSTON SUNDAY GLOBE, Boston, MA)

Ben and Jerry, meet Brenda and Ernie.

And Donna and Gayle and Eric and thousands of others who each year get a boost in starting businesses from the Service Corps of Retired Executives (SCORE). That's just what the Vermont ice cream duo of Ben Cohen and Jerry Greenfield did in their early years.

When a bank moved to repossess their first delivery truck, Ben and Jerry learned from SCORE that they could ask for a moratorium on payments. The rest of the Ben & Jerry's Homemade Inc. story is, as they say, history.

You might call SCORE the Gray Panthers movement of the business world. As a nonprofit adjunct to the US Small Business Administration, the organization was founded in 1964, in the time and spirit of the Peace Corps and Vista. Its volunteer counselors are retired business people who advise aspiring entrepreneurs, putting age and wisdom to work

on behalf of younger generations.

SCORE's activities peaked during the corporate downsizing of the early 1990's, when laid-off managers turned to entrepreneurship. Today, 12,400 volunteers are enrolled, working in 389 US cities, helping about 250,000 people a year. Their average age is 70 and they spend an average of 10 years with SCORE.

Brenda and Ernie Tracy haven't yet confronted the woes of debt and the wrath of bankers. But the Sharon, MA, couple have a dream, too - their own home-based business manufacturing braille menus for restaurants. Brenda is the salesperson and typesetter. Ernie who is blind and deaf, proofreads and binds the menus for delivery.

In a corporate biography, Ben and Jerry recall their SCORE consultant only as "Rocky." The Tracys have Jack Campbell, of Acton, MA, a retired marketing consultant in his 60s. As the principal SCORE consultant to their young company, Brailling Enterprises, Campbell has helped them write a business plan, learn to manage cash flow, and perfect their

salesmanship.

Brenda credits Campbell for stopping her from buying an inventory of costly braille paper before she had any orders. "SCORE is like my father," she says. "They are always there. Almost everything I have learned about business, I learned from them."

The Small Business Administration pays for an administrative staff of 12 in Washington and for reimbursement of volunteers' expenses. Clients pay nothing.

"But that's not the point, that it is for free," says William Cohen, 92, who has been with SCORE since 1972, making him the longest-serving volunteer in the country. "It is that we have expertise here that you can't get anywhere else. What you get here is ideas that can help you make it from people who have had experience."

A SPECIAL AWARD

Alice Turner, from Riverdale, Georgia, received a special award called The Deaf-Blind Citizen from Georgia Association of Deaf-Blind (GADB) during the Helen Keller Deaf-Blind Awareness Luncheon at Simpsonwood Retreat Center on June 22, 1997. She deserved the special award because of her enthusiastic help educating people about deaf-blindness.

In May 1996, Alice proudly received an Appreciation Award from Georgia Sensory Rehabilitation Center (GSRC). She volunteered weekly at GSRC to help the staff and clients learn about deaf-blindness and trained some of the deaf-blind clients how to use the TeleBraille. She went with Bob Green, deaf-blind specialist, to several different workshops to present deaf-blindness to different people. She was impressed by them.

She recruited some Interpreter Training Program (ITP) students and friends to be Support Services Providers (SSP). She opened minds and hearts explaining about the etiquette

of comfortably interacting with individuals who are deaf-blind. She wants to continue to educate and serve people who are disabled.

HERE AND THERE

Shadows in the Dark's braille pictured greeting cards are available individually, in sets of 10 or 20. The company offers birthday cards, as well as anniversary, thank you, Easter, St. Patrick's Day, Christmas, and other occasion cards. Individual cards are \$2.00; a set of 10 cards costs \$20.00, and a set of 20 cards costs \$35.00.

Mail your order to: Shadows in the Dark, 4600 Pine Hill Road, Shreveport, LA 71107-2716 or call (318) 459-1426.

* * * * *

Choco-Braille has braille greeting cards made of chocolate, reading "Happy Birthday,"

"Thank You," "Season's Greetings," and more. Each bar costs \$2.50; bars with nuts cost \$3.50.

For more information, or to order, call (718) 359-4466.

* * * * *

COOKING WITH FEELING is a new book that explains adaptive cooking techniques for blind and visually impaired people, and also gives recipes for everything from appetizers to desserts. Some of America's best chefs and restauranteurs have donated recipes for this cookbook.

To order the book, or for more information, write to the author, Deborah DeBord, 81 Cree Court, Lyons, CO 80540 or phone (303) 823-0337.

* * * * *

Xerox Adaptive Products has announced a price cut and new financing program for the

Reading Edge, a reading machine for the blind and visually impaired. It can read books, magazines, printed photocopies and documents with multiple columns. Xerox has lowered the price of the Reading Edge from \$5,495 to \$4,995. In addition, Xerox is offering customers a choice of zero financing on the Reading Edge, or an instant rebate if purchased by check or charge card. The new financing program is \$199.00 down payment and \$110.00 for 24 months. If you purchase by check or charge, you receive an instant rebate of \$495, a savings of almost \$1,000 from the regular purchase price.

Xerox has also introduced a financing program for the Out-Look video magnifier, a magnification system for those with low vision. The unit sells for \$1,795, but can be financed for \$99 per month for 18 months, with a \$198 down payment.

The Reading Edge has a one-year warranty and is available through a network of distributors. Outlook has a five-year warranty.

For more information, a product demo, or

the name of a distributor nearest you, call (800) 248-6550, extension 1, Xerox Desktop Document Systems, contact or call Karen E. Sunderland, (508) 977-2097.

* * * * *

The INTERNATIONAL NEWSLETTER FOR DEAFBLIND PEOPLE has resumed publication under a new editor. The magazine, published in Grade One braille, contains articles and information from many sources helpful to deafblind readers. If you are interested in receiving the magazine, which is free, contact: Lex Grandia, Editor, Prinsessegade 28, DM 9400 Noerresundby, Denmark.

IN A DARK WORLD

By HKNC student, Clarissa Darcy

My eyesight is now gone,
I see everything with my fingertips,
I may see things differently,
But inside my heart,
I see everything the same,
As the rest of the world.



NAT-CENT NEWS

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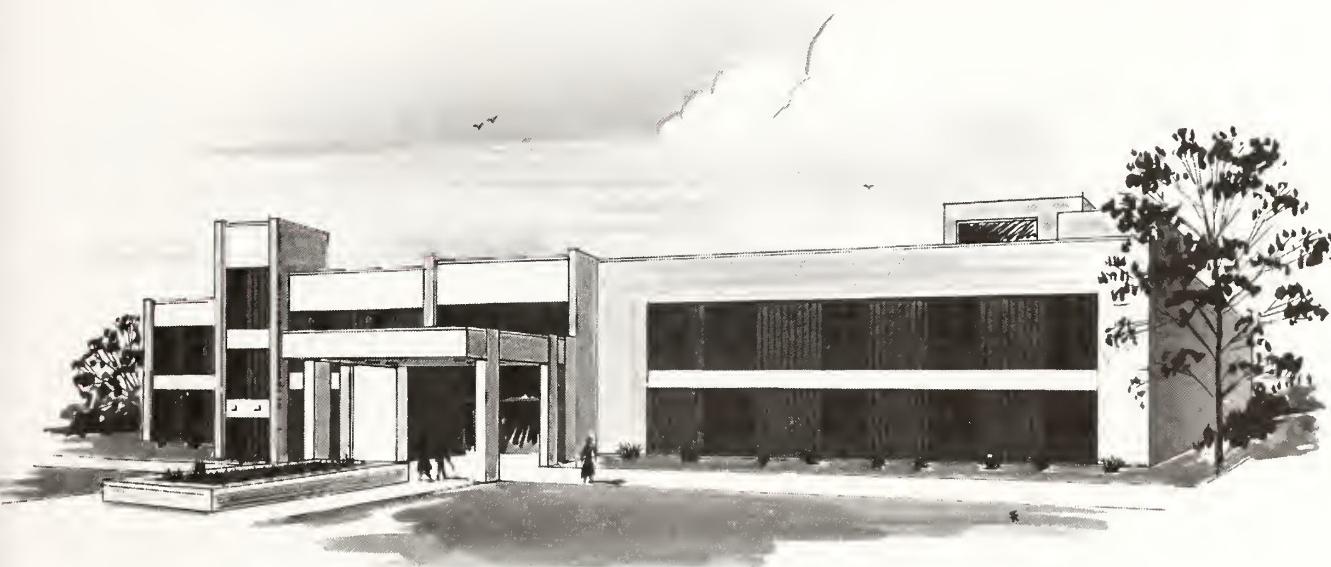
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EDITORIAL: RESOURCES PLEASE

By Robert J. Smithdas, LHD, Litt.D., LHD

During the past year I have received letters from deaf-blind individuals in various parts of the United States asking for information about assistive devices and other materials that can be useful to deaf-blind people. Requests for such items have run the gamut from braille watches and braille clocks all the way to used refreshable braille displays for computer buffs.

Obviously there is a lack of information on special items and sources of supply for materials and devices that can be helpful to the deaf-blind population. Recently I checked out my listing of reliable sources for information and catalogues, and I was surprised that the supply of such information has shrunk and also become more limited in scope.

Although there are catalogues available that sell special items for the blind and visually impaired, as well as catalogues containing devices for the deaf and hard-of-hearing, few of

them are accessible for deaf-blind individuals because they are offered in print, on cassette, or in recorded form; and if they are available in braille format, only a few are free on request.

For example, the National Federation of the Blind provides a free braille catalogue; the New York Lighthouse also supplies a catalogue in braille free of charge. But other suppliers, who provide print and recorded catalogues free, make charges for braille copies. If a deaf-blind reader wishes to keep up with new developments, it is often necessary to obtain the print catalogues and have them transcribed into braille at one's own expense.

These days, with so much emphasis being applied to the subject of braille literacy and accessibility of information in accessible forms, it seems odd that blind and deaf-blind readers have to pay for catalogues in braille that are supplied free of charge by vendors who provide large-print, cassette, and recorded copies. And to my knowledge, the only international catalogue that provides information on current aids and devices, including items useful to the

deaf-blind, is the guide currently available from the Royal National Institute for the Blind in London, England - in print.

As we train deaf-blind people to become more independent in handling their everyday problems, there is an increasing need to supply them with sources they can use to obtain information on a growing variety of subjects and assistive aids.

FIELD SERVICES

By Nancy Flax, Assistant Director
Field Services, HKNC

As you know members of the American Association of the Deaf-Blind (AADB) and volunteers are very busy planning for the 1998 convention - June 13 - 19, 1998. This year AADB has designated time for the Helen Keller National Center regional representatives and people from each region to meet as a group. The time slot is Thursday, June 18th from 1:15 p.m. to 3:15 p.m.

Wow! That means there will be eleven meetings going on at once. This is a new activity for us and we look forward to the opportunity provided by AADB.

Harry Anderson, president of AADB has appointed HKNC regional representative, Dorothy Walt, also an AADB board member, as liaison to field services and she is coordinating the plans for this activity. We will have note takers at each meeting so that a summary report can be made for the AADB board of directors, the regional representatives and other interested parties.

The agenda for the meeting includes: 1) general introduction by everyone; 2) brief overview by regional representative of their job and activities; 3) individuals sharing successful projects or activities, problem solving in their communities or states; 4) individuals identifying problems that they or others are experiencing in their local communities or states; and 5) ideas for an agenda for a similar meeting for 2000.

We would like to first focus on the sharing of success stories or problem solving strategies

that might be repeated in other local communities or states. What better place than the 1998 AADB convention to share and celebrate successes. We also need some time to share concerns or problems noted in local communities or states. It will be interesting to see if there are differences between the states. We will also ask people who attend if they would like to see a regional meeting again at the next conference and for any suggestions they might have.

As these field notes are being written, Martha Bagley, coordinator of the Older Adult Program, is attending an international work group meeting of professionals with expertise in working with elderly deaf-blind people. The group is meeting in Copenhagen, Denmark. It is expected that information from this meeting will be disseminated at a later date.

In February, the Texas School for the Blind and Visually Impaired held a state wide conference for educators and parents. C.C. Davis, our representative in the region, sent a picture of Pat McCallum, both a member of the

Deaf-Blind Multihandicapped Association of Texas (DBMAT) and secretary of National Family Association of the Deaf-Blind (NFADB), presenting a keepsake of the conference to Ralph Warner, president of NFADB. The smiles on their faces suggest that Texas had a very successful conference.



Ralph Warner (l.) receives his memento of the conference from Pat McCallum (r.).

Joe McNulty, HKNC director, was the keynote speaker providing an update on Individuals with Disabilities Education Act

(IDEA) and its implications for the education of deaf-blind children and youth.

HKNC's AFFILIATE NETWORK LOOKING TO THE FUTURE

**By Nancy Godfrey, Affiliate
Coordinator, HKNC**

Since 1974, the Helen Keller National Center through its Affiliate Program, has developed a nationwide network of state and local programs to meet the needs of individuals who are deaf-blind. The Affiliate Program provides assessments, consultations, recommendations, and technical assistance to the forty-two agencies currently enrolled in the program, and other related agencies nationwide. Half of the agencies are private, non-profit, and the remaining twenty-one are public, to include seventeen state commissions and/or departments for the blind and visually impaired.

Agencies or organizations generally enter the Affiliate Program through an annual grant

application process. This program provides temporary financial support to those applicants accepted. Each agency has a unique program. The money is generally used to hire a deaf-blind specialist who is responsible for the goals and objectives of the proposed project. Every year, all the deaf-blind specialists are invited to come to the Helen Keller National Center for a week of training, networking, and program information sharing.

Last spring, two agencies were accepted into the Affiliate Program. The Chicago Lighthouse for People Who Are Blind or Visually Impaired has been an affiliate since 1975. The deaf-blind program is currently supervised by Diane O'Neill. They were awarded an expansion grant in order to extend their program to individuals who are deaf-blind and are not able to come to The Lighthouse for services. They have hired a community instructor, Juan Bernal, to serve deaf-blind people in their residences. Services include identification and assessment, implementation of an individual service program, advocacy and instruction to other

professionals and volunteers to enable them to provide direct specialized services to deaf-blind people.

Columbus Colony Elderly Care, located in Columbus, Ohio, is the only Medicare and Medicaid certified nursing facility in the nation directed specifically toward people who are deaf, hard of hearing and deaf-blind. In addition to the 150 bed nursing facility is a 106-unit independent living apartment complex. The major service components include health care, therapy, interpreting and sign language instruction, socialization, recreation, nutrition, transportation, braille and large print transcribing, orientation and mobility, and counseling. The new deaf-blind specialist is Tom Gisler. The goals are to improve current services to the deaf-blind residents of the nursing home and the apartment complex, assist other agencies who provide long-term care for people who are deaf-blind, and conduct national outreach to identify and provide services to deaf-blind elderly people.

The 1998 application process will be held at

the end of April. We hope to add more new exciting agencies and projects to our Affiliate Program so that services for deaf-blind people can improve across the whole nation.

**HELEN KELLER DEAF-BLIND
AWARENESS WEEK
ACHIEVEMENT AND INDEPENDENCE
IN THE COMMUNITY**

By Barbara Hausman, Director, Public Relations, HKNC

SHARE HELEN KELLER'S VISION by participating with agencies and organizations worldwide in the Helen Keller National Center's 1998 Awareness Campaign which focuses on the achievement and independence of people who are deaf-blind - living, working and actively engaged in their communities as volunteers, advocates and role models.

This year's campaign features Richard McGann, aged 44; homeowner; husband;

Richard McGann.
Age 44.
Husband.
Founder of a LIONS Club.
Teacher.
Pittsburgh Steelers fan.
Community activist.

**Deaf-
Blind.**

Surprised? You shouldn't be. Richard McGann and thousands of people who are deaf-blind live independent and productive lives—thanks in part to the programs offered by the Helen Keller National Center. For more information about all of our services, call 1-800-255-0411 x275.



Share Helen Keller's Vision

Helen Keller National Center for Deaf-Blind Youths and Adults:
111 Middle Neck Road, Sands Point, NY 11050

Regional Offices: Atlanta Boston Chicago Dallas Denver Kansas City
Los Angeles New York Seattle Washington, DC

*Operated by Helen Keller Services for the Blind.
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employed for 26 years as an instructional aide, then supply manager, now braillist and teacher; president and co-founder of the first LIONS Club chartered by individuals who are deaf-blind; ardent Pittsburgh Steelers fan; active board member in his church, and at Pittsburgh's Planning Council and Task Force on disabilities, former vice-president of the American Association of Deaf-Blind (AADB), and much more.

His "non-stop energy, optimistic personality and great sense of humor" earned him the outstanding citizen of the year award five years ago from the Pittsburgh Post-Gazette, among other accolades.

Like McGann, over 50% of the population with deaf-blindness has Usher syndrome, a genetic disorder characterized by hearing loss, present at birth or shortly thereafter, and a

progressive loss of vision due to retinitis pigmentosa (RP). This past year, extensive research has identified specific gene mutations which may cause RP, so gene therapy holds tremendous potential for future treatment of Usher and other retinal degenerative diseases.

Undoubtedly, the increase in education, vocational training and employment opportunities over the past decade have enabled people with severe disabilities, like deaf-blindness, to acquire the skills needed for independence and involvement in their communities. But according to Tony Coehlo, chairman of the President's Committee on Employment of People with Disabilities (PCEPD), who introduced the landmark legislation, Americans with Disabilities Act (ADA) in 1990 as a congressman from California, "We still need considerable effort to change employer attitude. Most employers need greater exposure to workers with disabilities before the 'fear factor' is eliminated. Certain technological adaptations have significantly leveled the playing field in the employment area

by offering more adaptations and decreasing the emphasis on physical tasks."

On the positive side, PCEPD reports that 70% of the accommodations made by employers cost no more than \$500, and 21% were made at no cost - like moving a desk away from bright light streaming through a window (for one person who was deaf-blind.) On average, for every dollar spent on a job accommodation, the company gained \$32.80 on benefits, including increased productivity and savings on such expenses as worker's compensation and training of new employees.

Another incentive for employers is a federal "work opportunity tax credit" to businesses which employ people with disabilities: 35% of the first \$6,000 in wages per worker, (or \$3,000 for qualified summer youth workers), provided the employee works for 180 days or 400 hours and is certified as having a disability; 25% for less than 400 hours, but at least 120 hours; and 40% for 400 hours or more.

Today, people who are deaf-blind work at a host of jobs around the country from computer

programmer to assembly worker, chef, administrator, attorney, laundry worker and more. Though we need to improve employment opportunities and focus on getting people started in the job market, we must also focus on the youth of today.

Several years ago, Richard McGann was part of a national symposium on Education for Students who are Deaf-Blind, and he says that one of his goals is to encourage more youths to move into leadership positions. He even hopes to establish a junior AADB in the future.

Replication nationwide of the Pittsburgh LIONS Club, with an inclusive membership of deaf-blind, deaf and sighted-hearing members is another goal, along with establishing much needed housing and support services for this population. Perhaps his biggest challenge is trying to educate the public about the needs and abilities of people with dual sensory loss.

Originally proclaimed by Congressional resolutions and Presidential signature 14 years ago, awareness activities and events featuring information about significant vision and hearing

loss, or deaf-blindness, now occur throughout the year, beginning in June, the month of Helen Keller's birth date.

All citizens, health organizations, civic groups, libraries, schools and agencies are encouraged to plan state and local activities during the month of June, and especially during the week of June 21-27. A sample proclamation, a radio public service script, list of activities, 1998 poster, ad slicks, and this press release are available at no cost from the Public Relations Department, Helen Keller National Center, 111 Middle Neck Road, Sands Point, NY 11050, or by calling Barbara Hausman, 516-944-8900, ext. 325 (Voice), 516-944-8637(TTY) or faxing 516-944-7302.

COMING DOWN TO EARTH: CONTINENTAL AIRLINES AND THE LAW

By Douglas L. Parker, Director
Georgetown University Law Center

EDITOR'S NOTE: For most of its active history, the Helen Keller National Center for Deaf-Blind Youths and Adults has been periodically involved in cases where national airlines have refused passage on their planes to deaf-blind travellers flying alone and unaccompanied by guides/interpreters who could communicate with them. Even when a deaf-blind individual was a seasoned airline traveller with excellent communications skills, airline officials often denied passage because they felt the deaf-blind passenger would be a liability if emergencies arose during flight. They pointed out that such passengers would not be able to hear emergency announcements or receive needed instructions given to all the passengers on board the plane. They were concerned that deaf-blind persons would need special assistance

during flight, the communications would be difficult and that flight personnel would not be adequately trained to provide special services for them.

HKNC has always acknowledged the fact that there will occasionally be deaf-blind persons who are not capable of flying alone because they lack education, experience, and needed skills in communication, and we recognize that such individuals need to be accompanied by capable caregivers.

Over time, your editor has accumulated a thick file of correspondence and documentation relevant to several incidents in which deaf-blind individuals were denied passage on airlines unless they were accompanied by companions or caregivers, despite the fact that they were experienced and capable travellers.

In mid-February of this year, we received a message from Douglas Parker, Esq., director of the Georgetown University Law Center, Institute for Public Representation, in which he describes a lawsuit filed against Continental Airlines last April. We were particularly

interested in this case because the plaintiff was a former HKNC student who is currently attending college.

We wish to share Mr. Parker's description and information about the case with our readers because the decision was in favor of the deaf-blind plaintiff and sets precedence in such future lawsuits. This decision, handed down by a federal court in Washington, D.C., marks a milestone in freedom to travel for deaf-blind passengers.

Last April, we sent you a letter concerning a lawsuit we had filed against Continental Airlines on behalf of a client who is deaf-blind. The lawsuit was filed under the Air Carrier Access Act (49 USC Sec.41705) (the "ACAA"). Here is an update on the results of that lawsuit.

As I explained in last spring's letter, our client is a woman who is deaf-blind, fluent in English and currently enrolled in college, and who is an experienced airline passenger who has frequently traveled alone. In August of 1996, she flew alone from Washington, D.C. to

Newark, New Jersey, on Continental Airlines en route to Providence, Rhode Island. At Newark, she was met by an airline employee who knew some sign language and who assisted her in getting to the gate for her connecting flight. There was no suggestion that she needed to have an attendant to accompany her on the flight.

Once she boarded her connecting flight, however, she was approached by an airline employee and told that the airline's policy prohibited her from flying unattended. The airline wanted her to get off the plane and wait at Newark until she could get someone to fly with her. After an hour's delay, and over our client's protests, the airline found an off-duty flight attendant to sit with her (but not communicate with her) for the duration of the flight.

When she got to Providence, she called the airline and was told that she would not have to have an attendant when she flew back to Washington. After a two week visit in Providence, however, she went to the airport for her return flight, only to be told that an airline

attendant must fly with her on the flight back to Washington. The airline told her that in the future she would have to have an attendant and that she would not be able to fly alone.

Upon returning home, she sent a letter to the airline discussing the legal regulations that the airlines must follow and asking the airline to clarify its policies. When she received no response to that letter, she filed a lawsuit in federal court in Washington.

The lawsuit raised an important question about the rights of deaf-blind persons, and persons with disabilities generally, under the Air Carrier Access Act. Under the ACAA regulations adopted by the U.S. Department of Transportation in 1990, an airline can require a person with a disability to travel with an attendant only under certain narrow circumstances.

Specifically, the regulations (14 Code of Federal Regulations ("CFR") Sec.382.35) permit an airline to require a passenger with both "severe hearing and severe vision impairments" to travel with an attendant only if

the passenger "cannot establish some means of communication with carrier personnel, adequate to permit transmission of the safety briefing" required by FAA rules. If the airline and the passenger disagree over the need for an attendant, the airline must pay for the attendant.

As the case went forward, Continental Airlines took the position that even if a deaf-blind person can communicate well enough to understand the initial safety briefing, the crew can still find that they might have difficulty communicating in an emergency and can therefore require an attendant. In short, the airline said that it could ignore the specific requirements of the regulations wherever it was concerned about a passenger's safety.

We argued that that position flies in the face of the very carefully drafted regulations concerning attendants. We contended that if a carrier can apply a generalized concern about safety to undercut a provision as specific as Sec. 382.35, it might be able to do so in interpreting other provisions as well. If the airline had prevailed on this point, many of the protections

built into the ACIAA regulations would unravel.

The case was tried before a jury in federal court in Washington, D.C. last November. After a four day trial, the jury found that the airline had violated the regulations. The jury, following instructions on the applicable law provided by the judge, thus upheld our client's position that an airline cannot ignore the specific language of the regulations and substitute its own speculation about what might be safe. Our position was reinforced by the U.S. Department of Transportation itself, which agreed with our interpretation of the regulations and began an inquiry into Continental's policies. As a result of that inquiry, we understand Continental has now revised its training materials and staff manuals.

While the jury did not award our client any monetary damages, we felt that the case established an important point of law: airlines must comply with the ACIAA regulations and cannot substitute their own judgments about "safety" for the requirements imposed by the regulations. It also showed that deaf-blind

people have important rights when they travel, that they do not have to accept demeaning treatment from airlines, and that they can use the federal courts to enforce their civil rights.

We hope you will advise people who are deaf-blind and others about this case and alert them to their rights under the Air Carrier Access Act. The case is an important step. However, we are concerned that the problems faced by our client are not isolated and that deaf-blind people may still be subject to arbitrary and illegal treatment by airlines. We are therefore writing to each of the major airlines to tell them about this case and ask about their policies and procedures and about the kind of training they provide their employees. We will encourage the airlines to comply with the regulations and make a special effort to train employees to understand the rights of deaf-blind passengers. We will be happy to share with you and those you represent the information we receive.

If we can provide any additional information, please contact us.

Douglas L. Parker, Director, Georgetown University Law Center, Institute for Public Representation, 600 New Jersey Avenue NW, Suite 312, Washington DC, 20001-2075, (202) 662-9535, TDD (202) 662-9538, Fax (202) 662-9634.

CENTER OPENS NEW WORLDS FOR WOMAN

By Chandra Harris (Reprinted from The News-Dispatch, Michigan City, IN)

Nancy Brakenridge lives in a world with limited vision and limited hearing. But thanks to a year spent in New York at the Helen Keller National Center, the Michigan City resident has learned to cope with her limitations.

Brakenridge was born with a hearing loss and later, when she was 28, she was diagnosed with Usher syndrome, a genetic condition combining hearing impairment or deafness and retinitis pigmentosa.

Initially, she experienced night blindness

and then she noticed a loss of peripheral vision. She had problems navigating, even in daylight. "It was a progression over time," Brakenridge said. "In the first grade I had to attend special classes and wear a hearing aid but otherwise I was not affected while I was in grade school, high school nor the beginning years of college."

But then problems began to set in at work. "At first I thought other co-workers just had bad handwriting or the computer screen printed too small," she said. "It really became difficult for me. The entire work office looked like a blur and then I had to scan the computer screen left to right in order to read the entire screen," Brakenridge explained. "But every challenge I was faced with I dealt with."

That included the challenge of being terminated from her job after 16 years. "During my last few months at work, I sought help from the Lighthouse for the Blind in Chicago, to find adaptive devices that might help me on the job," Brakenridge said. "These were very costly to purchase and, in addition, they were unable to address my needs."

After one year at home, Brakenridge took the trip to New York that started to change her life. She entered the Helen Keller National Center in March 1995. "I was in search of answers," she said. "At the same time I was afraid. I was going to give the Center one week and if I did not like it, I was going to come back home."

The Center became her "home away from home" for a year. "At the Center I found friends that were just like me," Brakenridge said. "For the first time in my 43 years of life, no one outside of my family was questioning whether I really needed help or not. All of my teachers at the Center were willing and ready to help."

Barbara Hausman, public relations director for the Center, was one of those people who lent Brakenridge a helping hand. Hausman said at first Brakenridge was shy. "But as her trust level built up she just blossomed."

At the Center, Brakenridge received instruction in mobility and in how to use a cane. She learned American Sign Language and

tactual signing, she mastered grade I braille and learned how to live independently. "Some of the things I learned I do not use right now, but if I one day can no longer see at all I will have the skills to make it," she said. Hausman said, "At the Center we try to give everyone the skills they need so that they can return to their community and families."

Beyond learning life skills, Brakenridge pursued her own career goal of becoming a medical transcriptionist. She earned a certificate at Molloy College in Rockville Centre, NY, and then interned at a New York hospital in the pathology department to practice her "new, learned skills."

She has been back in Michigan City for more than a month, and has sent resumes to local companies. Brakenridge has also been testing her new skills by living independently. She wears 2 hearing aids and occasionally a vibrating device to let her know if the doorbell rings or if the phone rings. "I love to cook; as a matter of fact, I think of myself as a rather good cook," she said.

To cook, Brakenridge has specially designed utensils and measuring devices as well as recipes from Betty Crocker cookbooks, usually in large print. Besides cooking, she loves to go shopping, swimming, walking, exercising, horseback riding and reading.

To do some of the activities she loves the most she has to make use of her cane and her 3 pairs of glasses - a pair of sunglasses, a pair for reading and a pair for walking. "I may need a device to help me do some of the activities I love but I can do them," she said. "As long as I can do them somehow and I have a support system behind me, my spirits will always be up."

Brakenridge said her family has always supported her. One special person in her life who is most supportive of her independence is her boyfriend of 5 years, Jim Meeham. "We first met through a singles group at a church and we clicked the first time we met," she said. "While I was in the Center for a year he called me at least once a week," she said. "I thought for sure this would be the perfect time for him

to leave me, but he didn't."

On July 26, 1997, a stormy night, Meeham proposed to Brakenridge in his car while they were parked in the Marquette Mall lot. Brakenridge is planning to have a small wedding in 6 months to a year.

"Good things continue to happen to me," Brakenridge said. "I am just as human as the next person."

WORTHY OF PRAISE

By Susan Parr, Deaf-Blind Specialist, South Dakota Service to the Blind and Visually Impaired.

Timothy Jackson, a young man from Sioux Falls with Usher syndrome I, is the winner of the 1998 South Dakota Governor's Outstanding Employee with a Disability Award. This award is given annually "to an employee with a disability in recognition of outstanding achievement in competitive employment and for providing inspiration to other individuals with

disabilities." Tim received his award at an honor luncheon in Pierre, South Dakota, on March 5, 1998, hosted by South Dakota's Lt. Governor Carole Hillard. Tim's wife, Ruth, and parents, Milt and Sue Jackson were also on hand to share in Tim's honor.



(Photo by Loren Tullberg)

Tim Jackson (r.) receives his award from South Dakota Lt. Governor Carole Hillard as John Jones, Human Services Secretary looks on.

employed at SPS Payment Systems of Sioux Falls in the area of P.C. Support Systems.

Tim's many accomplishments include inclusion on the Dean's List at Gallaudet in 1988-89, past president of the Gallaudet

Tim was a student at the Helen Keller National Center for 10 weeks in the summer of 1987 before graduating from the South Dakota School for the Deaf in 1988. He graduated from Gallaudet University in 1995 with degrees in accounting and computer information systems. For the past two years, he has been

Association of the Deaf-Blind, member of the Sigma Phi Epsilon fraternity, current president of the North Central Association of the Deaf-Blind in Sioux Falls, and membership in a local LIONS Club.

Always confident in his abilities rather than focusing on disability, Tim says, "I feel that I can achieve a high level of job performance and success in a short time." His ultimate goal is to become a computer programmer and a business owner by creating his own home-based computer service.

In the meantime, Tim continues to enjoy his job while keeping very busy with several hobbies and pastimes, such as fishing, reading, computer games, and connecting with friends via the internet on America On-Line. He would enjoy hearing from old friends (and new ones!). His address is: 100 N. Krohn Place #10, Sioux Falls, SD 57103. E-mail: TJack88095@AOL.COM

Tim's family, friends and co-workers are all very proud of his recent award as are the service providers who have worked with him

through the years. But most importantly, Tim is deservedly proud of himself. This award is just one example of Tim's accomplishments in proving that deaf-blindness does not have to be an impediment to a full, productive, and happy life.

HKNC ANNOUNCES NEW SUPPORT SERVICE PROVIDER (SSP) PROGRAM

By Stacey Sullivan, Senior Instructor and Deborah Harlin, Supervisor, Communications Learning Center, HKNC

The Helen Keller National Center (HKNC) has been providing its students with the opportunity to access the community on an individual basis through a special pool of volunteers called Support Service Providers (SSPs). This program has been in effect for the past two years. It is modelled on an existing program which originated in Seattle, Washington. The goal of this program is to enable individuals who are deaf-blind to access

the community with assistance, while retaining autonomy.

SSPs are trained at HKNC by a variety of experienced staff who are skilled in communication techniques and mobility. The SSP assists in providing visual and auditory environmental information to the consumer. He/she also facilitates communication with the public and is a conduit through which the individual accesses independent travel. The primary goal is to promote independence in a supportive, non-intrusive manner, while providing assistance within the community. Some activities in which students may request an SSP include: errands, ride/guide to the airport, bus or train, read the student's mail or newspaper, and/or recreational activities (shows, dancing, museums, restaurants, library, beach, etc.)

Many of the volunteer SSPs are recruited through local interpreter training programs, deaf studies programs, and deaf service centers. Most of the SSPs know some sign language prior to volunteering. They are all provided

with a 4 hour training session which includes: orientation and mobility, communication techniques, the role of the SSP, deaf and deaf-blind culture and a variety of simulation activities that are not only informative but fun.

The long range goal of the SSP program is to expand services to sites throughout the state of New York and eventually nationwide. Progress towards this goal has already begun - a group of interpreter trainees from Poughkeepsie, NY, recently traveled to HKNC to participate in an all-day workshop. This group returned to Poughkeepsie with plans to set up a similar program in their area, and have requested future training from HKNC staff once the program is initiated.

The training of this group provided HKNC staff with feedback for future trainings. The group reported high levels of satisfaction with the workshop which offered hands-on experiential opportunities. It also gave the participants an invaluable opportunity to expand their skills before beginning future employment. The mutually beneficial relationship presents an

excellent framework for modeling future workshops geared toward community expansion of the SSP program.

The SSP program currently provides students with SSPs and actively recruits and trains new volunteers. It is expanding on a daily basis, so much so that the last training session in February was full and people were put on a waiting list for the next session.

The SSP coordinators, Stacey Sullivan, Kathy Zarate, MJ Shahen and Maricar Marquez have put in their own time to develop this program and expand upon it. The program provides deaf-blind individuals with a means of accessing their community while instilling self-confidence and independence. For more information concerning the SSP program the above coordinators can be reached at the Helen Keller National Center at (516) 944-8900 (voice), (516) 944-8637 (TTY).

JUST AN ORDINARY GUY

By Cynthia Ingraham, HKNC Regional Representative, East Central Region

It seems to be a common feeling for many adults who have had a wide range of experiences in their lives that they need to share these life experiences with members of the younger generation. Often this need for sharing information is viewed as an obligation by the former group, while it seems a drudgery to the latter. However, there are always exceptions to this rule, and Richard McGann is a notable example.

Chosen to be the poster person for this year's Helen's Keller Deaf-Blind Awareness Week sponsored by the Helen Keller National Center (HKNC), a native of southwestern Pennsylvania and a long-time employee of the Western Pennsylvania School for the Blind, Richard, who has Usher syndrome, has been active in promoting services for deaf-blind people for many years, and he takes great pleasure in sharing his life experiences with

others.

He has been an inspiration and support model to many deaf-blind consumers and budding professional workers in the fields of deafness and deaf-blindness.

In the spirit of this year, I had the opportunity to spend time with Richard for two days in March. I saw how he worked and how he shared his life story of coping with Usher syndrome with groups of children at the Delaware School for the Deaf in Newark, Delaware, and then with a group of aspiring interpreters at the Community College of Philadelphia, Pennsylvania.

He piqued the curiosity of many of the students and faculty members at the school in Delaware. They had never experienced meeting a deaf-blind adult "who was just an ordinary guy." Richard intrigued his audience with his experiences as a deaf youngster coming to grips with the loss of vision and all the frustrations it involved, and then the sense of accomplishment he felt when trying to find a job.

During his visit to the school for the deaf,

Richard had an opportunity to meet a six-year-old boy and his brother, seven, both of whom have Usher syndrome type I. Matthew and his older brother, Brian, were intrigued by the mere thought of being able to communicate with Richard. The different method of communicating - tactile communication - was something that young Matthew picked up quickly. Matthew's natural curiosity, and Richard's patience and encouragement sparked instant teamwork and Matthew was hooked on this new method of communication.



Richard (c.) shows Matthew (r.) his braille watch while older brother Brian looks on.

Richard, realizing he had found a new friend, began sharing jokes and animated stories with Matthew. This made Matthew feel comfortable with the new world of deaf-blindness, one in which he is trying to find his way. The two new friends exchanged e-mail addresses and promised to keep in touch.

One final lasting impression that Richard had on Matthew was his ability to autograph one of the HKNC Deaf-Blind Awareness Week posters, which he signed and presented "with love."



Richard and Matthew using tactal communication.



Richard shares an animated story with Matthew.

The following day, Richard and I co-presented a program to a group of interpreter training students at the Community College of Philadelphia. These budding interpreters were preparing for the upcoming convention of the American Association of the Deaf-Blind, which will be held in Connecticut this summer. Richard and his wife, Karen, have been providing similar workshops on interpreting for people who are deaf-blind to other groups of students for years.

Watching the wide-eyed amazement exhibited by these students, mingled with their apprehension, brought back memories of my own exposure to the AADB convention back in 1985. While my first experience at an AADB convention was somewhat overwhelming, frightening and exhausting, it was very rewarding and was enriched by the support and encouragement provided by support service providers (SSPs) during the preliminary workshops and throughout the entire week of the convention.

Students attending the workshop took turns interpreting for Richard, and guiding him during the duration of the workshop. They had ample time for practicing platform and voice translation skills, transliterating and tactile communication. By the time the workshop ended, all the participants were exhausted, but still had enough energy left to go out for dinner with their new friends!

Those two days with Richard enabled me to see the significance of "giving back" to others. Anyone who has ever questioned the value of sharing a story with a youngster, or serving as a mentor of a class of budding interpreters, could learn a lot from Richard. The compassion and sincerity that he brings to sharing his life experiences with others is exemplary.

This year's theme for Helen Keller Deaf-Blind Awareness Week addresses the reality that Richard is just an ordinary guy - a loving husband who enjoys sports; a person with a great gift for sharing and getting involved in - and giving back to - his community.

HKNC'S TECHNOLOGY CENTER

By James Belanich, Adaptive Technology Coordinator, HKNC

The Helen Keller National Center has a new Technology Center. For the past few years, computer instruction has been done in the Communications Learning Center and the Vocational Services Departments. Opened in June, 1997, the Technology Center, occupies the offices previously used by the Technical Assistance Center on the first floor of the Training Building. Now, computer and adaptive technology training is centralized, combining the expertise of both departments to expand the training available at HKNC.

Jim Belanich, the adaptive technology coordinator from the Communications Learning Center, and Joe Sampino, an employment training specialist from the Vocational Services Department are now providing classes in the area. Darcel Jackman, an employment training specialist from the Vocational Services Department, also teaches a few classes in the

area. Scott Stoffel, an instructor's aide and former HKNC student, was also teaching classes in the Technology Center, but unfortunately, he left HKNC in December of 1997 and moved to Pennsylvania.

The move is part of HKNC's goal to provide quality training in the use of computers and adaptive technology to individuals who are deaf-blind. In the new training area, the students are being introduced to computers with adaptive technology like braille displays and screen magnification programs. Students are learning how to use word processors, spreadsheets, data bases, braille translators, and several other types of programs.

In addition, students are shown how to access the internet - surfing the web and sending e-mail all over the world. Some students are being taught how to use stand-alone adaptive technology, such as: the Braille Lite by Blazie Engineering, the TeleBraille by Telesensory, and a variety of CCTV's. As technology continues to progress, the training provided at HKNC will also continue to progress.

The new Technology Center consists of three classrooms for individualized instruction. There is also a computer lab for student use and a computer repair/electronics training room.

HKNC is making a continued effort to meet the needs of the ever-changing field of technology by continually up-grading the equipment. In the past few years, the Center has been able to obtain computers and adaptive devices with the aid of private foundations and organizations (New York Mercantile Exchange, Ridgewood Savings Bank, HumanWare, I.B.M., and Fleet Bank). With the help of other institutions, HKNC will hopefully be able to keep expanding, enabling individuals who are deaf-blind to take part in the technology revolution.

As we near the end of the millennium, HKNC is preparing for the 21th century by focusing on how computers and the use of adaptive technology impacts on individuals who are deaf-blind. This new Technology Center shows the commitment of HKNC's effort to offer cutting edge training.

In the past few months, HKNC has made recent purchases, which consisted of a few Pentium computers, the most recent version of Zoomtext, two PowerBraille Braille displays, a Telebraille III, and a disk drive accessory for the Braille Lite.

VETERINARY TEACHER OVERCOMES CHALLENGES OF DISABILITIES

By Carla Bray (Reprinted from The Red and Black, University of Georgia, March, 1998)

Dr. Linda Medleau may not be able to see the dog she's examining, but, with the help of her students, she can "feel" her way to understanding what's wrong with it. Medleau, a teacher and dermatologist at the School of Veterinary Medicine, has no night vision, only 10 degrees of central vision which severely limits her peripheral vision and has been diagnosed as "profoundly" deaf.

Medleau suffers from Usher syndrome, which is characterized by the Foundation for

Fighting Blindness as a serious hearing impairment and progressive loss of vision caused by retinitis pigmentosa, a degeneration of the retina. Medleau said she was diagnosed with the disease when she was 18, but she noticed she had a serious vision problem much sooner. "When I was 16, going out on dates, I realized I couldn't see as good at night," she said.

Medleau teaches veterinary dermatology, a field in which vision is important for examinations. But Medleau said if she has a case history of the animal and someone to describe what the ailment looks like, she can determine what the problem is.

Medleau relies heavily on slides as visual aids for her classes. She can no longer see the slides, but she has them memorized and goes over them each night before class with Lynn Reece, who assists Medleau in class. Reece said she acts as Medleau's eyes and ears in class. She tells Medleau which slides are next and points to the areas on the slides that Medleau is discussing. She also holds an

assisted listening device that transmits to Medleau's hearing aid.

Medleau said the most difficult adjustment for her was realizing she had to do things differently. She said meeting a woman from the Helen Keller National Center helped her put things into perspective. "She told me it doesn't matter how I do the job as long as I get it done," Medleau said.

After that, Medleau began using a cane, which served both as an aid in getting around and as a visual to people, letting them know she couldn't see. She soon gave up the cane for a friendlier aid, a black labrador named Lotus whom she said is much better company. "She keeps me socially involved," Medleau said. "People would never ask me, 'How's your cane?'"

And those around her say she keeps a positive outlook on life. "She is an awesome lady," said Jenni Hatcher, a junior from Ringgold, an assistant to Medleau during the week. "I've never seen anybody as determined as she is." Reece agreed saying Medleau has a

wonderful attitude about life. "She seems to focus on the positive, ignore the negative and just keep going," she said.

When she attended veterinary school at Ohio State University, Medleau kept her vision problem a secret from her professors and most of her classmates. "I imagine I would still be trying to get into vet school if they knew I had two disabilities," Medleau said.

She said she had to ask her professors to repeat questions directed to her, and that dim lighting made it difficult to take notes. "I sat beside another vet student and copied word for word her notes, and that's how I got through vet school," she said.

But Medleau said she was lucky in school because her central vision was perfect, and she was able to see well enough to do surgery. She said she will one day lose all her vision, so this fall she plans to go to the Helen Keller National Center in New York, where she will learn various independence skills, including braille.

After that, Medleau said she has every intention to continue teaching at the University.

A NEW WORLD OPENS FOR LOCAL RESIDENT

(Reprinted from the FORUM, Queens, NY)

Finding a job IS a job...for anyone! But, as Mrs. Green walked through the aisles of the Pathmark grocery store in Whitestone, NY, on her weekly shopping trip after work, she thought, "This is close to home and would be a great employment site for my son, Ricbet."

Today, Ricbet is successfully employed in the supermarket's Bakery Department with rave reviews from his supervisor, Lou Zavanzo. Ricbet happens to be deaf and is legally blind.

After attending the Lexington School for the Deaf in New York City, and St. Joseph's School for the Deaf in the Bronx, Ricbet was referred to the Helen Keller National Center (HKNC) for vocational rehabilitation training. His vision was deteriorating and he had to learn some new skills for independent living, mobility and communication.

During his training he tried different types of jobs and seemed to enjoy food service. He

worked at nearby St. Francis Hospital's cafeteria and then volunteered at HKNC's residence cafeteria for four months after completing his training.

"I really learned a lot and had a good experience at HKNC," said Ricbet. "Now I'm teaching Lou how to sign and he knows fingerspelling. I'm independent. I'm skilled."

Accompanied by HKNC job coach, Lisa Feliciano, Ricbet had an interview with the store manager and was soon hired to work four days a week. With Feliciano's assistance, he learned specific tasks. He removed the frozen dough, set it up on trays and slid the trays into the refrigerator for baking the next day. Zavanzo said he would teach him some baking by Christmas, but within two weeks Ricbet's production was so efficient his boss showed him how to use the machine that mixes the batter for muffins, and then how to bake them.

"The Pathmark staff were so accommodating," said Feliciano. "They put information into large print, they wanted to learn American Sign Language, and they just

love him! His supervisor has already learned some simple signs, 'You and I are friends,' and 'good work.' They supplied him with a uniform, white jacket and pants. He uses communication cards and writes notes with a black flair pen in his notebook."



Ricbet using a laminated list of instructions.

"It took a long time to find a job," said Mrs. Green. "He left HKNC in 1995. There was a lot of frustration. Employers were hesitant, nervous and fearful about needing extra help.

They weren't willing to give him a chance. This hurts when you see your child, who wants to be independent, getting rejection after rejection. But, I advocated for him, along with the Center's staff. Remember, I'm not always going to be around. I want him to have a life. He's a grown man."

"This experience with Ricbet has reawakened a passion to do the right thing," noted Zavanzo. "In a world that's increasingly making decisions based on dollars and cents, it is refreshing to be able to make a decision based on right and wrong."

Another positive outcome - Zavanzo's goal is to advocate for more jobs at Pathmark for people with disabilities.

LEARNING LIFE SKILLS

By Valerie Faciane (Reprinted from the East New Orleans Picayune, New Orleans, LA)

Jean Valley is a very busy person as she makes her way around the kitchen at the

Resources for Independent Living offices on Poydras Street. She is making lollipops and loving every minute of it. She melts hard candy in the microwave and then carefully pours it into molds in the shape of angels and sports figures. She places sticks in the molds and puts them in the refrigerator to harden. A few minutes later she removes the candy from the molds and is happy to see that her lollipops were a success.

It is a labor of love for Valley, 32, who is legally deaf and blind. She has very little vision left and would not be able to hear without hearing aids. She performs her task under the watchful eye of Kristi Mora, the deaf-blind program manager at Resources for Independent Living, a nonprofit agency that provides services to, or on behalf of, disabled people so they can live successful, independent lives in the community. The agency serves about 20 deaf-blind clients, Mora said.

To live as independently as possible is Valley's goal. In November 1997, she returned to New Orleans after spending a year at the

Helen Keller National Center (HKNC) where she learned how to cook by herself, ride in a taxi, keep track of her money and other skills.

"I fried an egg all by myself," she said proudly. "I can cook my own mashed potatoes and pizza." She also has cooked herself a hamburger. Valley said using a stove used to frighten her because she was afraid of getting burned, but now she feels confident that she can maneuver around her kitchen safely.

At Resources for Independent Living, the skills she learned at the HKNC are being reinforced and expanded. Valley has learned how to use bus transportation for disabled people and will continue honing her math, reading and braille skills.

After Valley receives special cooking utensils from the HKNC, Resources for Independent Living personnel will go to her home to teach her to use them there.

Valley said one of her Christmas wishes is to get an instrument that vibrates when the doorbell or telephone rings, in case of fire or when someone knocks at the door. Her other

Christmas wishes are to get a job and to have a guide dog to help her get around in unfamiliar places. She said she would like a housekeeping job or one working with special children.

Valley, who lives in Gretna with her mother, said she is glad that she is back home but that her experiences at HKNC really have made a difference in her life. "I made some good friends in New York," she said.

EXPERT CRAFTSWOMAN CHALLENGES HER DISABILITIES

Want an idea on how to keep warm or decorate that extra room? Contact Kozy Komforters by Sharon in Middleton, Idaho.

Sharon Grove, who has Usher syndrome II, has been quilting for several years. She has won blue ribbons and a Grand Champion at the local Canyon County Fair in Caldwell in 1993.

Her comforters are nice and cozy! They make great gifts for birthdays, weddings, anniversaries, new baby, graduation, or for that

special college student for his or her new dorm room. They are also great for holiday gifts such as Valentine's Day, Mother's Day, Father's Day, Christmas.

Choose your own pattern and colors. Wake up under the "Morning Star," done up in shades of blue. Bet you won't get cold all snuggled up under a "Snowball" comforter. A "Lover's Knot" is perfect for the newlyweds in their favorite colors. How about a multi-color done up in "Dresden Plate" or "Grandma's Fan" that has been embellished with lace. Even that new baby can have his or her own comforter. A "Sunbonnet Sue" for her and "Overall Sam" for him. The "Farmer and His Wife" is cute too or that cuddly little "Teddy Bear" they all love.

Sizes vary from crib to lap, twin to king and all sizes of waterbeds. Also available are wall hangings, placemats, napkins, table mats and runners for that special holiday. New patterns and ideas are coming in all the time.

Sharon is now taking orders for custom made comforters, asking clients to select their patterns and color combinations.

Comforters have gone to states as far away as Massachusetts, Virginia, Oklahoma, Texas, California and Washington. In Idaho they have gone as far north as Lewiston and as far south as Mountain Home with several in the Treasure Valley.

All comforters are made with extra loft batting for a fluffier feel, they are hand tied, or can be machine quilted for an additional charge. Please allow up to 3 weeks for completion of work.

For more information call: Sharon Grove, 1-208-585-3303 or write to Kozy Komforters, 12162 Longstreet West, Middleton, Idaho 83644.

HERE AND THERE

Now available from Arkenstone, Inc., the Very Easy Reading Appliance (VERA) scans a print page and reads it aloud for people who have visual disabilities.

VERA is controlled by an easy-to-learn

keypad which has tactiley marked over-size keys and contrasting color labels which make the keys easy to distinguish. Each key has only one function so users cannot get confused when using the keypad. It is said that the product is ideal for both adults and young children who have visual limitations.

The complete VERA, including keypad, reading processor, and scanner is \$3,155.00. A supplemental color display is an additional \$300.00.

Also available from Arkenstone are two other new products, the Bookworm from Handitech in Germany, and the Braille Rabbit.

The Bookworm is a walkman-size device with an eight character braille display, primarily meant to be used as a portable text reading device. The device's braille display can be set to scroll automatically under the reader's fingertips and, after some practice, readers may be able to read electronic books in a braille format. The Bookworm can fit easily into a purse or large pocket, and can hold many braille books in its internal memory. Currently the

device costs \$1,500.00 in Germany.

The new Braille Rabbit, the RET-40, is a new refreshable braille display weighing less than two pounds and only one inch thick. Only 11 1/4" wide and 4 1/4" deep, it easily fits into a handbag or shoulder bag with note-taking devices such as Braille Lite, and can be used with most desktop computers. The Braille Rabbit's 40-cell display can be situated above or below the computer's keyboard by using an ingenious system for inverting the braille dots 180 degrees.

Arkenstone is a source of many useful assistive devices for the blind and visually impaired. To inquire about its products or to ask for additional information, contact Arkenstone, Inc., 555 Oakmead Parkway, Sunnyvale, CA 94086-4023; Tel.: 1-408-245-5900; 1-800-444-4443.

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Bill's Big Type Cookbook is an easy-to-read large-print collection of recipes for main dishes,

side dishes, desserts, salads, rolls and breads, and much more for the visually impaired chef. A sample unit copy costs \$20.00, plus shipping and handling, plus state sales tax for Minnesota residents. Volume 1 is the Dinner Cookbook, and volume 2 is called the Sweets Cookbook.

For further information or to order, contact: RBP Products, 5045 Dawnview Terrace, Golden Valley, MN 55422-3530; for orders with credit cards by phone, call (888) 522-0506.

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The American Red Cross has recently released **DISASTER PREPAREDNESS FOR PEOPLE WITH DISABILITIES**. This book is designed to help people with physical, visual, hearing, or cognitive disabilities prepare for natural disasters and their consequences. Included are sections on understand disasters, disaster supplies, making the home or office safer, and creating personal support networks. The book is available on two audio cassettes for \$5.00. Contact your local Red Cross chapter

for further information on prices and formats.

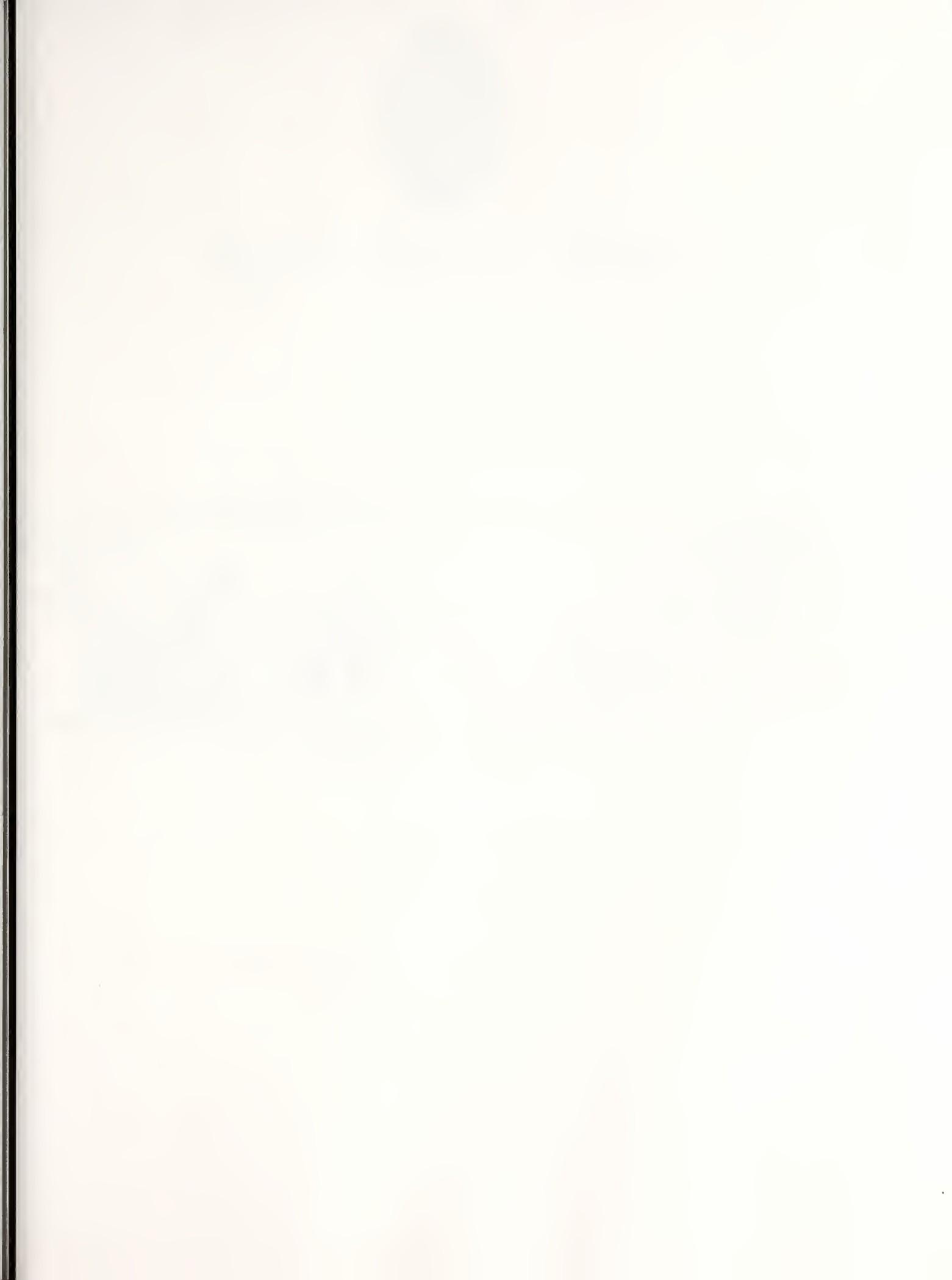
The third edition of AMERICA'S TELEBILITY MEDIA is now available. It contains 260 pages of contact information and reference data; offers 850 periodicals, 50 broadcast producers, 20 newspaper columnists, 46 newspapers for the blind, and 12 professional media organizations. It is a valuable reference guide for families, consumers with disabilities, libraries, public relations and rehabilitation professionals. AMERICA'S TELEBILITY MEDIA can be obtained for \$30.00 per copy in print, or on diskette in ASCII format. Contact: National Telebility Media Center, P.O. Box 1488, Columbia, MO 65205; Tel.: (543) 445-7656.

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Greeting cards in large print and braille, scented, for all occasions are now available from Prophecy Designs. Large print cards,

which feature 24- and 36-point print, are full-color originals. Braille cards feature printed messages, repeated in braille, and include descriptions of the scenes on the front of each card. Prophecy Designs also offers free name personalization in hand calligraphy, with braille personalizations available for a nominal sum. Envelopes are provided for all cards.

To order or for further information, contact Prophecy Designs, P.O. Box 84-D, Round Pond, Maine 94564 for a free catalogue.



NAT-CENT NEWS

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EDITORIAL

NEEDED: A HISTORY OF DEAF-BLINDNESS

By Robert J. Smithdas, LHD, Litt.D., LHD

There is no denying that the twentieth century, now drawing swiftly to its close, has produced a series of notable changes and improvements in education, technology, and social progress that have benefited American citizens who are deaf-blind. In the past ten years alone, there has been an upsurge in the number of conferences about deaf-blindness and its problems, books written by and about outstanding deaf-blind individuals, and books and videos describing methods and techniques for educating and training Americans who lose sight and hearing. A growing number of achievers who are deaf-blind are being brought to public attention by the media.

All of these factors, combined, have been important and beneficial in promoting work in the field of deaf-blindness from a professional and consumer perspective. We are now

developing specialized training programs and support services throughout the United States and its territories which make the public aware of the potentials of deaf-blind individuals when they are provided opportunities to develop and use their skill and talents as independent citizens.

In the past, Helen Keller used to be the only model held up to deaf-blind students for emulation; now modern deaf-blind people are using new methods and technologies that have come into existence in the last fifty years.

To this writer's knowledge, there is no official, comprehensive history of work for the deaf-blind and the accomplishments of deaf-blind achievers - people who, in spite of the loss of sight and hearing, have overcome the unique problems of their dual disabilities.

Most of the outstanding progress that has been made in the field of deaf-blindness has occurred during the second half of this century through improved programs of education, rehabilitation, research, and the training of professional workers who provide necessary

support services.

Sources of historical information about deaf-blindness do exist, but they are widely scattered and poorly documented and researched. It has only been recently that certain unusual personalities, such as Morrison Heady, a poet and inventor who was deaf-blind, have been given their fair share of recognition.

Today there appears to be a determined effort to prove that there is such a social condition as "a deaf-blind culture." But there is no definitive history that integrates the intellectual, artistic and social achievements of a society sharing mutual interests and goals. A culture must have a history of proven facts tracing its beginnings, its progress and its growth to give it substance and reality.

A FRESH START FOR 1-800-FLOWERS AND HKNC

By Barbara Hausman, Director, Public Relations, HKNC (Reprinted from HKNC UPDATE, Summer 1998)

As one of the fastest growing companies in America and the world's largest florist, 1-800-FLOWERS is committed to increasing employment opportunities for people with disabilities - and HKNC was one of its first partners.

Providing a variety of "real" work experiences for HKNC students during their vocational rehabilitation training at the Center is a primary goal. "Targeting national companies with headquarters nearby is important to HKNC staff because our students return to their home communities and may eventually find permanent work in a branch or regional office of the company," explained Kathy Mezack, HKNC vocational services coordinator.

"1-800-FLOWERS is a young company and everyone has been supportive and willing to

help. Their staff is very busy, but they take time for us; perhaps to discuss a creative program for a new student or make a telephone call regarding employment in a retail store. We've had around 10 students working at their headquarters in Westbury."

Floraversity Director at 1-800-FLOWERS, Neil Halloran, praised HKNC's job coaches, Angela Sausa and Lisa Feliciano, and their students. "This partnership is good for the community and us; the HKNC employees are on time, reliable and responsible. They're getting paid, they're being trained and it makes them feel more confident. We began our cooperative venture in June 1997, first with clerical jobs, then in the marketing/merchandising and accounting areas here at our corporate site."

Halloran spearheaded a training project which offered elementary floral design workshops for 30 hours, resulting in a certificate from their "Floraversity." Former HKNC student, Susan Schueller, spent two hours with one of their florists to determine if this class would be appropriate for her.



Mark Nemery and Susan discuss her work.

Susan and fellow former student Billie Goodnight, worked as a team with Mark Nemery, 1-800-FLOWERS Baskets Manager. "They compiled a marketing tool - a three-ring binder - by clipping, photo-copying and indexing photos of products from catalogues by price point and item, such as fruits, cookies and cheesecake," said Nemery.

"They were great. They took such pride in their work and they were much more particular than I was. They helped me create an ongoing competitive analysis; a way to measure our company against our competitors. These pictures enhance the grids and figures the computer spits out. Because we're growing so fast, we are always physically moving around and they adapted so well to our changes. One



Billie Goodnight enjoys an afternoon out with volunteer, Mykle Freedman.

day Billie found a location, a table, and off they went to work. It was really HIS project!"

In the Accounting Department, Terry Hagen said the "HKNC students come in for a whole week once a month to attend to our accounts receivable. They fold, collate and stuff monthly statements for all corporate customers and retail house accounts. They've even caught a few mistakes, too! We'd forgotten to staple two pages together and they said, 'This one is a duplicate.' They take their work seriously and feel like this is THEIR company and that they are part of 'the team'... which epitomizes 1-800-FLOWERS' philosophy!"

A VICTORY, MEASURED BY THE HEART

By John Hanc (Reprinted from NEWSDAY,
Long Island, NY)

Sometimes we think we know about people we've never met. We have a picture, an image in our minds, of how those people should look

and sound. And sometimes one of those people comes along to shatter that image, completely and forever. Such was the case this past August when a blind and deaf woman named Maricar Marquez completed the 11th annual Seacrest - Tobay Triathlon in Oyster Bay, Long Island. Not only did Marquez finish the 1-kilometer swim, 12K cycle and 5K run event, but she finished it in 1:51:46, well ahead of many of the 1,100 athletes who participated.

As she approached the finish, the word spread around Roosevelt Park. And when people crowded around the finish line, they saw someone they didn't expect to see. "I'm in awe," said race volunteer Kathy DiVeglio. "She's so beautiful and so intelligent."

DiVeglio, like most of us, can be forgiven for her surprise. Even today, in a society supposedly more aware of those with physical challenges, few of us have met anyone like Marquez. Our idea of what a deaf-blind person should look and sound like probably comes from Hollywood. Perhaps from Patty Duke playing the role of the young Helen Keller in "The

Miracle Worker."

"Helen Keller was a very strong woman," said Marquez, 26, who works as a recreation specialist at the Helen Keller National Center in Sands Point. "But her view of life was different. And that was a different time."

Marquez has done things many non-physically challenged people wish they could do: She's gone to college and graduate school; she's a rock climber; she has skydived, explored caves and traveled extensively. The triathlon was just the latest of what she calls her "adventures."

Of course, that is not to minimize the difficulty in staging this adventure. Unlike Keller, Marquez does not speak, but communicates through tactile sign language - meaning she spells out words into the hands of an interpreter. To complete the triathlon, she required the help of four such interpreters from the Center. In the swim, she was flanked by Kristen Layton and Jim Belanich, who, through a series of taps and touches, kept her on course in the waters of Long Island Sound. She rode

through the hills of Oyster Bay on a tandem bike with Susie Morgan, who steered and tapped on the handlebars to communicate any upcoming turns or changes in gear. Marquez would feel the vibrations of the taps and respond accordingly. Finally, she ran the last 3.1 miles of the race tethered to a guide runner, D'Andrea Weeks.

"It gives me goose bumps watching this," said second place finisher, Bob Spina, Jr., of Massapequa as he tried to follow the wordless, rapid-fire hand-signed conversation between Marquez and her interpreters, who crowded around to congratulate her after the race.

"This is nothing unusual for Maricar," said Dan Ebenau, who served as the technical support member of her team. Ebenau, a rock climbing instructor from Long Beach, taught Marquez at an indoor climbing facility. Since then, they've become good friends, and their differences have vanished. "She's really inspirational to work with," he said. "The way she experiences the world is totally different, not necessarily worse, just different. It's as if

she's speaking another language."

In any language, what Marquez has achieved is extraordinary. A native of the Philippines, she was born with Usher syndrome, an inherited disease that left her deaf at birth and with diminishing eyesight (she has been legally blind most of her life and now has only about 10 percent vision). Her family moved to Ontario, Canada, when she was a child. She came to the United States for graduate studies at Gallaudet University in Washington, D.C., and then, last year, to the Helen Keller National Center.

Marquez trained three months for the triathlon, riding a stationary bike, swimming in a pool and running on a treadmill. Still, she admitted before the race, "I was nervous." That's partially because she and her team had not actually tested their buddy system until race day but also because she knew she would be the object of attention and curiosity. She always is.

"It's a challenge," she said, "because I have to constantly educate people about deaf-blindness." On race day, we all got an education.

HELEN KELLER AND ME

By Janet Sand, former student, HKNC
(Reprinted from HKNC UPDATE,
Summer, 1998)

I am 50 years old, have been married 30 years, and have two daughters aged 22 and 18. The older one has just announced she is getting married in August! I have Usher syndrome, Type II, which means I have nerve deafness and retinitis pigmentosa, which leads to blindness. I have worn hearing aids since I was five and had lip-reading lessons and speech therapy throughout childhood.



I attended regular public schools, even changing every two or three years because of my father's government job. I spent two years in Hawaii and graduated as an A student from high school in Canberra, Australia. I earned my bachelor's degree in International Relations from American University in Washington, D.C.

and then worked as a management analyst in the Veterans Administration in D.C. for six years. I stopped working to become a stay-at-home mom, and for 15 years was an active volunteer at my daughters' schools and with the (then) RP Foundation.

About five years ago, I no longer felt that I was satisfactorily dealing with my hearing loss. I was missing more and more conversation - I found it more frustrating and exhausting - so I slowly started avoiding conversation. My deteriorating vision was also having an impact. I felt trapped at home and unable to get around by myself. I was bored, depressed and unable to deal with life outside the confines of my home.

In 1996, my husband, Sid, and I attended a national conference. The visual and auditory stress was almost unbearable. But, for the first time, I was exposed to people who understood my dual problems and offered positive suggestions for dealing with my mental, emotional, and physical needs. I heard about the Helen Keller National Center (HKNC),

contacted my local HKNC representative, met with her and my Maryland vocational rehabilitation counselor, and flew to New York for a two-day visit. I was thrilled. I loved the atmosphere at HKNC and enrolled on January 5, 1998.

It's difficult to summarize the program. What I found was an incredible concentration of specialists in every aspect of dealing with deaf-blindness. They were all "tuned in" to each student on a very individual level. They were anxious to help me "be what I can be" and I worked harder than I ever had in many years. Every student's schedule was customized to fit his/her needs, as defined by student and staff, and student interests.

Besides my one-to-one sessions during the 8 class periods with instructors in independent living, low vision, communications, adaptive technology, computers, speech, mobility, and more, I met with my case manager, a women's group and leisure committee each week. I had a busy schedule and it suited me to a T!

Every evening and weekend, optional

activities, on-campus and off, were available, such as dining in local restaurants, sight-seeing, bowling, a walk in the preserve next door, bingo - even wall climbing and ice skating. I went out with an SSP (support service provider) for the first time to a book store, and I went to a really nice Italian restaurant with two "Usher II" fellow students.

I began learning ASL and started Grade II braille and nighttime mobility lessons. I cooked blindfolded (very interesting and fun, as well as useful), learned a lot on the computer (getting into Windows 95, Excel and Word lesson books and exploring the Web), got acquainted with TDD's and the CCTV. I attended a Deaf Culture night class at Hofstra University, which was interesting in itself, as well as helpful to prepare me to take college courses at home.

I met several students who arrived at HKNC with no intention of getting a job, but most, if not all, of them changed their minds and left eager to get back into the work force.

Many deaf-blind people are so beaten down by their disability that they're depressed and

lack the self-confidence to think in terms of working. HKNC gets them out of that self-defeating way of thinking, gives them hope, everyday coping and living skills, and inspires them to do something interesting and productive with their lives. The Vocational Training Department is very pushy and has everyone doing some kind of work, both on- and off-campus. Most try several kinds of jobs.

Indirectly, I'm benefiting from the reflection and self-examination which HKNC stimulates. I'm slowing down and I'm more patient; I accomplish more with less stress. Lastly, I've made friends with people like me (even on the Internet) who understand what I'm up against.

OPEN LETTER TO DbI REVIEW

(Reprinted from the DbI Review, the magazine of Deafblind International)

Corrina Veesart is a 16 year old deafblind teenager who lives in a small coastal town in central California. Corrina is a member of the

American Association of Deaf-Blind and has attended their national conferences since she was 11. Corrina has written a letter to DbI Review and talks about her life and interests which include writing and dancing. Corrina's poem, "Chamber of Corrina," was published in a recent issue of News From Advocates for Deaf-Blind, a publication of the National Family Association for Deaf-Blind.

EDITOR'S NOTE: The following letter and poem, written by Corrina Veesart, a bright and attractive sixteen year old girl from California, who has visited the Helen Keller National Center in the past. Her enthusiasm and upbeat perspective on life, despite being deaf-blind, is contagious and inspiring.

Dear DbI Review:

I am an active, regular teenager and I attend a typical high school. I am among two other deaf girls who go to my school. I am a fluent signer using ASL signs. I am eager to learn in school and get very good grades.

I am profoundly deaf. I can hear some very loud sounds if nearby. I cannot read lips since my vision is not good enough for me to see the movement of the lips. I can see from about five to six inches from my face. Beyond that length is blurry. It's hard to see the signs clearly so I often use tracking. I can make out shapes ahead of me but it is almost impossible for me to make out what they are until I come up close. I also have a hard time telling if the ground is flat or sloping. For example, I can't see steps very well. I hate to use my cane though. In the dark I can see nothing.

I enjoy making up stories. I usually write names and then make up stories related to the names, often about a group of teenage girls who are best friends or sisters who never argue. I have a wild imagination and love to invent stories and characters. My ability to write came naturally. My teacher urges me to write down my stories so others can share my imagination and learn some of the secrets that my mind is hiding from them.

I also enjoy reading. I carry a book almost

everywhere I go along with my magnifier since I can't see small print. I can also read Braille. I am known as "bookworm" since I LOVE books. My mother can hardly drag me away from my books when I need to go to bed or other small matters.

I also love the sense of rhythm. I love dancing. It gives me a feeling of freedom. I just found out I succeeded in making the cheerleading team at school. I also take ballet at a dance studio with a whole class. I have an interpreter with me. My dance teacher tutors me after class or once in a while on Sundays to help me understand the movements. I know I can do anything I put my mind to.

Sincerely, Corrina.

CHAMBER OF CORRINA

Paint me like I am
Chocolate brown hair
Wavy like the ocean swells
Paint me shy as a koala bear
But my shyness fades like dawn fades away

to sunny day
And I become as talkative as a blue jay
Paint me curious to learn
And eager to bring smiles to others
Paint me with curious eyes
Green as the wood
Of Wisconsin
Paint me cuddling a child
So tenderly singing softly
Why don't you touch your Wand to me and
Paint me perky springing about jumping around,
chanting my cheer to myself...
Paint me as loving as a mother gorilla to her
young child
I love my friends and care for them.
Paint me surrounded in a room of roses and
angels
All whispering glory and
Singing softly
Just paint me as a cheerleader
Though I'm not yet one
But want to be
Paint me kicking my legs from side to side
like a Kangaroo.

ON THE JOB

by Barbara Hausman, Director, Public Relations, HKNC (Reprinted from HKNC UPDATE, Summer 1998)

He hails from Phoenix, AZ. After a year of college he was employed as a meat packer for six years. Robert Tarango was born deaf with good vision. Three years ago he learned that he had Usher syndrome II when his peripheral and night vision began to deteriorate. Robert wanted to improve his vocational skills. He had always lived with his family, and felt that he needed independent living and mobility skills.

In May, 1996, he entered HKNC. "Robert was very social, well liked and easily integrated into his peer group," said his HKNC case manager, Suzanne Ressa. "He was extremely interested in current affairs and ordered his own subscription to Long Island's daily newspaper, 'Newsday'. He participated in all recreational



Robert and Sutton Place store manager, Eileen Colondrio.

trips, loved New York City, and soon met new friends at local deaf clubs." During training, Robert worked at St. Francis Hospital in the mail room and print shop. He lived independently in the Center's rented apartment in town.

After completing his training, Robert was offered a temporary, but full-time, position as food service worker in HKNC's Residence cafeteria, which expired after six months. He searched for a permanent job and affordable apartment. His goal was clear - independence, not dependence on SSI.

Focused and determined, Robert walked into a Pathmark food store, was interviewed and was hired part-time. Next he applied for a position at nearby Sutton Place Gourmet, a specialty food store in Woodbury, LI.

"Robert answered my ad in Newsday," said Eileen Colondris, Sutton Place store manager and Robert's direct supervisor. "He works from noon to eight p.m., five days a week, and receives a full benefits package. He's a pleasure! He always has a smile."

During a recent visit to Sutton Place Gourmet, Robert pointed to a distinguished gentleman nearby and said, "There's the president; I met him." Tom Johnston, president and chairman of the 14 unique stores located throughout the northeast, was warm and quick to praise his staff, including Robert. "We believe people are our #1 asset. That's the concept we've built our company around. Robert personifies what we're all about. He's fun and food is fun. That's who we are!"

Overall store manager, Chris Snell, confirms that "Robert is an independent, persistent and competent young man. He seeks extra tasks when he completes his routines and helps me keep our retail space safe by paying attention to any hazards on the floor."

Robert has worked at Sutton Place for four months. "After work, I walk next door to Pathmark and finish there around midnight."

Today, Robert is enjoying his independence and chosen lifestyle - in a suburb of New York City, which he loves.

LIVING INDEPENDENTLY IN A WORLD WITHOUT SIGHT AND SOUND

(Reprinted from the SILENT NEWS)

Born in the Dominican Republic, he lived with his family in the Virgin Islands for several years and then moved to the U.S. settling in the Bronx in 1991 when he was 17 years old. He spoke no English. His proudest moment occurred on October 10, 1997, when he became an American citizen. Today, Bienvenido Batista - fondly called Bien - is a gifted woodworker, a natural leader among his peers, tall, good-looking and he happens to be deaf-blind.

"I was born deaf and had good vision until I was 8 or 9 years old," explained Bien. "I thought there was something odd going on, but I ignored it. When I was 16, I couldn't see at night. I tripped over things. I couldn't see a step in front of me. Then I found out I had Usher syndrome. I was really angry. My parents explained it was a genetic condition so I couldn't express my feelings to them. I was

the only one in my family with a disability." Though his vision has stabilized, Bien could become blind at any time.

Bien learned some English and American Sign Language during his years at the Lexington School for the Deaf in Queens, NY, and after graduation he entered the Helen Keller National Center for comprehensive rehabilitation training in August, 1996.

"At first I wasn't interested in learning mobility techniques," said Bien. "As time went on I realized it would give me more independence. I joined an Usher support group and thought to myself, 'could everyone here have Ushers?' In the beginning I was reserved. Everyone talked openly about their lives. As time passed, I became an active member and began to learn about this unusual syndrome.

"I was also involved in the Town Hall Committee - a group of five students who try to resolve problems identified by other students living in the Residence. For example, we had an open room in the Residence where students could make TTY calls or use the TeleBraille and

other computer technology. But there was NO privacy. So we built wall dividers in the woodshop to alleviate that problem.

"I also initiated a 'buddy' system to help new students feel more comfortable. This began when I accompanied staff to meet a new student at the airport. I showed him around the campus, introduced him to other students and described the safety and emergency procedures. Soon a committee was established and other students became involved."

As part of his HKNC training, Bien had an opportunity to explore several "work experiences" out in the community. At Trunz supermarket he labeled and priced different items. "Even my co-workers started to learn some ASL and my boss would sign 'home' or '20 minute break now'.

"I tried assembly and soldering work at Clever Devices and was amazed that I could do such small, intricate work. At Subway Sandwich shop in town, I prepared food and garnishes, sliced meat on wax paper and set up different work stations. Each day my boss

offered me lunch, and after calling a cab, I went back to the Center and devoured my sandwich.

"One of my experiences, at a nearby mini-department store, was boring because they didn't have 'label guns' and I had to peel off the price stickers from a large sheet and apply them to each product.

"But I was really into the woodshop program at HKNC. My instructor, Mak Gharabaghi, encouraged me to think positively. I started with basic skills and he guided me into really challenging projects. My final project was a six foot cabinet with glass doors, 12 glass shelves and a recessed light. I built it, stained and varnished it."

"Bien could be a cabinet maker's assistant, if given the opportunity - he's ready!" said Mak proudly.

A few months before completing his year and a half training period, Bien lived independently in one of three HKNC rented apartments in town. There, he applied all of his classroom skills in a "real life" situation, such as paying rent and utility bills, managing all

housekeeping and cooking chores, budgeting, planning and shopping in nearby King Kullen, reconciling his checkbook, using an ATM, and more.

"We have seen Bien blossom as an excellent, motivated student," added Kathy Mezack, HKNC coordinator of vocational services. "He's a true role model for other students and has worked closely with Mak to develop new and exciting woodshop projects. He would be an asset to any employer. He's committed, reliable and serious about producing quality work. I foresee a very successful future for Bien."

What about plans for the future? On February 6, 1998, Bien completed his HKNC training. "I'm feeling a little sad about leaving the Center, but I'm working with the HKNC job placement specialist to find a job. Together we are searching for resources within my neighborhood in the Bronx - perhaps stock work at the Gap, Modells or Footlocker. You know, I've got it all together! I'm not concerned about being safe or how to get around out there in the

community. I also hope that if anyone reads this story, my words will connect with someone out there - someone like me with severe vision and hearing loss - who will realize that s/he can become an independent person."

EDITOR'S NOTE: Bien is now employed full time by HKNC as a Habilitation Specialist in the Residence.

A PLACE TO CALL HOME

By Victor R. Caivano, Associated Press

It's a long way from a refugee camp in Saudi Arabia to a suburb near Dallas. For Ahmed al Ghazawi, the route is even longer: He is deaf, mute and legally blind. An injury robbed 25-year-old al Ghazawi of all sight in his right eye. And Usher syndrome, a genetic disorder, is progressively stealing the vision that remains. He has so little vision in his left eye that he could not see a horse right beside him.

But Anne Marie Weiss, a volunteer who helps relocate Muslim refugees, is al Ghazawi's

pathfinder - the defender of his future. Her goal for refugees is "to bring them into the mainstream of life and to make them fulfill their potential."

Al Ghazawi's family, all Shiite supporters, faced persecution by the Iraq government and exile in the late 1980s. For more than five years, they lived in a desert camp in Saudi Arabia. Then in 1996, the International Rescue Committee in New York City brought them to the United States.

While kinship is important in Iraq, his family felt no sense of duty toward al Ghazawi when they got to Dallas. In fact, they ridiculed al Ghazawi's efforts to learn, calling him stupid. "They openly laughed at his dreams of studying and working," Ms. Weiss says. "Work? Get married? He was crazy, they said."

Last summer, al Ghazawi's family accused him of a knife attack and he landed in a Dallas jail. Two days later Ms. Weiss received a call from the jail's nursing supervisor and he was released. When the police started investigating, the family dropped the accusations.

Wherever home was, al Ghazawi could not go there again. So Ms. Weiss teamed him with another refugee in a one-bedroom apartment in north Dallas, in a neighborhood of Bosnian Muslims and Somalis. With a wide smile, he approached everyone, trying to communicate with flailing arms and quirky sounds.

Jennie Reeves, of the state's Commission for the Blind, started teaching him reading, writing and signing and two Mormon women helped with homework. But he needed more.

Al Ghazawi attended the Helen Keller National Center in Sands Point, NY, which provided him with one-on-one classes and dozens of activities. Besides math and speech, he learned to master life skills: how to buy groceries, where to cross the street.

Three months after his arrival at the Center last November, al Ghazawi began to work - cleaning and making sandwiches in the Center's kitchen, and folding boxes at Pizza Hut. After visiting his employers, Valerie Chemla, his job supervisor, was optimistic: "They were very impressed."

There's no doubt that al Ghazawi is willing. "I really like that," he says of his work, in sign language. "It makes me happy. It's wonderful." The plan? Work up to a regular routine of 8-hour days - difficult to endure, Ms. Chmela said, for "anyone who has never worked before."



Ahmed experiences snow for the first time with HKNC staff, Valerie Chmela (L) and Brenda Muir (R).

Al Ghazawi still cannot sign fluently or understand abstractions such as time. Even the concept of money thwarts him. Where does it come from? How to spend? "I need him to be realistic, yet he can't be," said Audra Moran,

his case manager and counselor.

Looking at a map, al Ghazawi points at Dallas and signs "home." And home, in the future, may mean near other deaf-blind people who can sign. "We hope," Moran says, "there is a place like that in Texas."

SUPPORT GROUPS AT HKNC

By Audra Moran, Case Manager
and Ilene Miner, Consulting Clinical
Social Worker, HKNC (Reprinted from
HKNC UPDATE, Summer 1998)

The students served by HKNC are diverse in terms of their life experiences and come from every state. Many have never met another deaf-blind person before. Students have often undergone considerable stress and loss before arriving at the Center, as vision and hearing continue to change. This may include job loss or change, loss of friends, family pressures, changes and loss of role in the community, and loss of favorite activities and pastimes. Those

who have never met another deaf-blind person or who have had no rehabilitation may have fears about the future.

To ease arrival at HKNC and to provide role models, several support and discussion groups have been set up. The objective is to provide a safe environment to discuss issues of importance and to get support and feedback from peers. Currently there are three active groups: the Usher Support Group, the Young Adult Group and the Women-In-Transition Group. Some have gone through several evolutions and changes as student needs and desires change.

The first group, for people with Usher syndrome, Type I (characterized by profound congenital hearing loss, retinitis pigmentosa, vestibular dysfunction), started in 1993. It is open-ended; people can join as they arrive. This group is comprised of people who are culturally Deaf and use ASL as their preferred language. There is no voice interpreter.

There are currently two facilitators, Kathy Zarate, who has Usher I and teaches braille at the Center, and Ilene Miner, the clinical social

worker. There is discussion about events at the Center, feelings about vision loss and family issues, and information about Usher syndrome and its genetics. Students often say that the group provides a safe place for them to open up about what they are thinking and feeling. At this time, many members have children and are comparing experiences in their families as a parent with Usher syndrome.

The Young Adult Group is comprised of individuals with varying communication styles who have different deaf-blind etiologies. The group is unified by the fact that all are dealing with the transition from adolescence to adulthood. It is currently facilitated by Audra Moran, case manager, and Ilene Miner.

It is an active group, discussing fears about living independently, sharing triumphs of living in an apartment on campus, relationships with families, finding people to date, questions about work, concerns about going home and whether there will be isolation, becoming independent, and learning to assert oneself. There is always a balance of laughter and serious discussion.

As the numbers of students with Usher syndrome, Type II (moderate to severe hearing loss with retinitis pigmentosa and other deaf-blind conditions) grew, a new group was formed. Members used spoken English as their primary mode of communication and it became known as the Oral Deaf Group. This ultimately evolved into the Women-in-Transition Group, facilitated by Audra Moran, Lisa Honan, case manager, and Mia Kelley-Bock, case manager supervisor, and includes both individuals who use sign language or spoken English primarily. Issues discussed include: divorce or separation, career change, return to work or cessation of work, changing visual and/or hearing condition (which each member is experiencing to some degree) and other life events.

When students arrive, HKNC case managers inform them about the groups, and they can opt to join, depending on space availability. Groups are comprised of 6 to 10 people with interpreters to match each member's communication needs.

The groups have been a challenge. Members

have different communication needs and may be at very different points in their lives in terms of their thoughts and feelings about becoming or being deaf-blind. The student population is ever-changing and new needs develop and old needs change. Students and staff together continue to respond to these issues, recognize the need for ongoing assessment and revision when necessary. Groups will continue to provide a safe environment for members to discuss relevant issues and concerns, and their members will continue to cultivate new friends and mutual support.

ONE DEAF-BLIND MAN'S DREAM

By Bert Riedel, Conifer, Colorado

Eighty six years old, deaf and blind from Usher syndrome, my dream has been realized. My name is Bert Riedel and I have a walking path of my own!

Let me explain a little as to why this is so important to me before I tell you specifically

about the path. I laid down my dental tools 43 years ago, at the age of 43, to face a new life because of my genetic characteristic. Thirty years ago I was fortunate to have a beautiful guide dog, Duchess. I had enough hearing to guide my dog who valiantly gave me the freedom to travel on my own. She is gone long ago and so is my hearing. On Father's Day in my 86th year, I recovered that wonderful sense of independence again by means of a path built by my loving son, John, and daughter-in-law, Mary.

In the beginning of my transition to a sightless and soundless world, I was blessed with the companionship of wonderful children who developed an ability to report to me my surroundings so that I could recognize where I was and what I was "seeing" in my mind's eye. I learned to love nature because of the wonders of young humans who wished to share things of natural life that were so valuable.

In time, these young humans, growing up, had themselves become enamored of the beauty of nature and the fun of sharing it. Thus, we

traversed the hills and mountains of Maine, later enjoyed the beauty of Illinois, and thence to California. Life went by and 57 years of marriage made life a truly beautiful experience. Last year that part of my life came to an end as my wife, Helen, died and I became a widower.

I now live in a new environment with new people, my son and daughter-in-law, who live in the mountains of Colorado and are avid lovers of the mountains and all things growing. They have a large tract of land at 8,500 feet of elevation. They decided to find a way for me to find some independence and we all decided that a walking path would be just the right thing. So, they hewed out a path for me that begins right at the deck off my lower level apartment in their home in Conifer.

The path is about 4 feet wide and is covered with pine mulch so it is soft and easy on the feet. Of course, they had a bulldozer come in and level off the path so that there are no bumps and drop offs that could cause me problems. They put in 4 by 4 posts about every 20 feet and strung a strong rope along the 260 foot

length of the path. Now all I do is walk out my door, head off my deck and pick up the guide rope.

I walk on my own as long and as far as I like. Ten laps and I've done a mile! At the end of the path is a little sitting area with a bench and a table. Here I can sit and picture the area as John and Mary have described it to me on my electronic brailler.



Bert relaxes on his bench with his two companions.

There is a forest of pine all around me and the pines cover the ridges I view. There is a

meadow down below where elk love to graze, and as I face west, I get profound "views" of the Rocky Mountains.

We have a wonderful dog, Rocky, a black Australian Shepherd and Bernese Mountain Dog combination, who joins with me on my walks and enjoys sitting with me at the bench. And all around me is a profusion of wildflowers.

Best of all, as I begin the path by my deck, I have a garden which commemorates my wonderful soulmate, Helen. She loved gardening so much that I'm sure she looks down with a happy heart at our creation.

It is difficult for normal folks with hearing and sight to realize fully the meaning of having the freedom to walk a path on my own. The rolling path on the hillside plus the variations of smells and breezes, sun and fog are so vivid and wonderful.

Since the sun shines here almost 280 days a year, when I depart on my walk, the sun invariably brushes my face often in concert with a cooling breeze. Around me are forests of pine. There is a tremendous aroma of pine

scent and the surrounding wildflowers plus other forms of growth combine with the heat of the sun's rays to instill a remarkable feeling of joy. Continuously, I am reminded of the visible aspects of the environment described to me on my electronic brailler. In my own way, I am seeing and receiving the gifts of normal humans and searching the awesome wonders of nature.

Success and freedom like this is pure happiness.

What a beautiful gift that my children contributed to their dad on Father's Day! My life is less because of the loss of my wife, but more because of the many new and exciting opportunities that are opening up to me. Walking on my own path on my own schedule at my own pace is an opportunity that I am enjoying every day.

If you'd like to share any of your experiences or respond to any of mine you can feel free to contact me at (303) 697-7297. My son or daughter will be able to get a message to me.

HERE AND THERE

The READER'S DIGEST has introduced a new large-print version of its flagship magazine. THE NEW READER'S DIGEST EDITION FOR EASIER READING has a bold new format. It is printed on lightweight, non-glare paper in single-column format for easier reading and contains bright colored photos and artwork. Published monthly, it contains all the text and favorite sections from READER'S DIGEST, plus additional stories and information.

Subscription rates for twelve issues are: \$12.95, United States; \$37.95 (U.S. currency), Canada; and \$48.95 (U.S. currency), international. For ordering information, call (800) 678-9746.

* * * * *

The American Association of the Deaf-Blind is distributing its 1997-98 DEAF-BLIND CONTACT DIRECTORY. The directory is free to members of AADB. Nonmembers may

obtain a copy for \$10.00, in either braille or print format. The directory contains listings for deaf-blind individuals, personal service providers, clubs and other resources for deaf-blind people, telecommunication relay services and contact information for sources of special needs products.

For further information, contact: The American Association of the Deaf-Blind, 814 Thayer Avenue, Silver Spring, MD 20910-4500; or call TTY (301) 588-6545; FAX (301) 588-8705.

* * * * *

Outreach for the Blind and Deaf-Blind offers bibles and other materials in braille as well as a lending library. To find out about their services, contact Floyd Rhoads, Outreach for the Blind and Deaf-Blind, 4341 Edmondson, Indianapolis, IN 46226. Or call (314) 549-3433.

Ann Morris Enterprises, Inc., 890 Fams Court, East Meadow, NY 11554, has its new 1998 catalogue of products available for distribution. The catalogue is larger than before, with over 175 new products for the blind and deaf-blind consumer. It is available in large print, cassette and computer disk. Braille copies of the catalogue cost \$10.00 per copy or \$6.00 per copy if included with an order. Call toll-free (800) 454-3175 or (516) 292-9232. You can fax your order to (516) 282-2522.

* * * * *

Would you like to receive your Sears credit card bill in braille? If your answer is yes, call (800) 633-0815.

* * * * *

A handbook concerning reasonable accommodations as defined by the Americans With Disabilities Act (ADA) has been produced by the Department of Veterans Affairs Blind

Rehabilitation Services Committee on Reasonable Accommodation. The handbook provides a succinct and explicit overview of the law, gives examples of requests for reasonable accommodation, a definition of reasonable accommodation and several law cases. For a free copy, call Margie Donovan, VIST Coordinator, at (415) 750-6604. Please specify your choice of large print or ASCII computer disk.

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EDITORIAL: THE PRICE OF INDEPENDENCE

By Robert J. Smithdas, LHD, Litt.D, LHD

Achieving a significant measure of independence as a deaf-blind person is a highly desirable goal, but one that is difficult and expensive to attain.

Rehabilitation and training can teach a deaf-blind individual methods and techniques of daily living that will help provide a sense of security and personal adequacy in ordinary living conditions, but when the deaf-blind individual returns to community life, the scenario changes. Where are the resources for finding employment, and support services that will provide assistance for special needs? How to obtain those highly specialized - and often expensive - aids and devices that can make life easier without sight and hearing?

Recently a friend in Illinois wrote to me complaining that he had been in contact with his state's rehabilitation agency for several years, asking for assistance in finding employment. A

highly motivated and capable man, he was obviously frustrated in his efforts to find a job.

Henry Viscardi, founder and president emeritus of Human Resources in Albertson, New York, coined the slogan, "Give us the tools!" But it is also important to know where you will be able to use the tools once you have them. And that is where the states need to take over.

Unlike most other countries, the United States is comprised of fifty individual states, each with its own systems for providing for the welfare of its citizens, providing special equipment and needed basic support services. Most programs are far from comprehensive, still in the development stages, but that end is growing.

This year the Helen Keller National Center will celebrate its thirtieth year of operational existence. It is remarkable that HKNC has been so instrumental in influencing programs in the various states. Through its National Training Team, National Technical Assistance Center, and Affiliate Programs it is still helping to train the necessary professional workers who

eventually will be able to provide essential services to deaf-blind men and women throughout our country.

AFTER TRAGEDY, SOME PEOPLE FIND THEIR CALLING

By Linda Saslow

Reprinted from THE NEW YORK TIMES,
November, 1998

"The Phoenix factor" is what Dr. Janice Stefanacci calls it - the quality that allows some people to rise above grief and anger in the aftermath of a personal tragedy.

"Their lives are torn to ashes, but they find something inside of them that gives them the strength to contribute and make a difference," said Dr. Stefanacci, a clinical psychologist with a private practice in Manhasset.

"They turned meaninglessness into meaning," she said, "so that the tragedy of their lives wasn't in vain. Many of the best fighters were just living normal lives when lightning

struck."

The individual profiled here is among many on Long Island who have used personal adversity as a springboard to make a significant contribution to Long Island.

Mitchel Shapiro, 46, legally blind and severely hearing impaired, travels throughout Long Island speaking at schools and civic organizations about the Foundation Fighting Blindness and about overcoming obstacles.

For Mr. Shapiro, a personal struggle began more than 25 years ago, when he was told he had Usher syndrome, confirming what he already knew: that he was losing both his hearing and his sight. The symptoms had started at 8 years old, when he was told he needed to wear a hearing aid. When his vision also began to fail, a retinal specialist diagnosed the retinal degenerative disease that brings with it a loss of hearing.

The year 1994 was a very rough one for Mr. Shapiro, as he remembered. "Following my divorce a year before, our family business was sold, my girlfriend broke up with me, my vision

and hearing continued to get progressively worse, and I was severely depressed," he said. "I felt like I had reached rock bottom.

"Then I came to an awakening. It started with a poster with the message: 'Your greatest weakness is your greatest strength.' That poster nagged at me for two and a half days until I finally got it - my greatest weaknesses, my vision and my hearing, are my greatest strengths. I could either give in and feel sorry for myself, or take control of my life."

Through his father, Mr. Shapiro learned of The Foundation Fighting Blindness, a national eye research organization dedicated to finding a cure for retinal degenerative disease. He decided to attend a meeting of the Long Island Chapter. At the end of the meeting, when one of the leaders asked if anyone could do public speaking, Mr. Shapiro volunteered.

Realizing that he first needed personal tools to function more effectively, Mr. Shapiro learned Braille, sign language and received mobility training. He then began his new role as public speaker and advocate.

"My message is that if you're affected by a disability, you have choices as to what you're going to do about it," he said. "If you sit back with self-pity, you get nowhere in life. Or you can choose to do something to make a difference. Those who have the courage and persistence are life's winners."

Mr. Shapiro has become a frequent speaker for The Foundation, as well as for the United States Organization for Disabled Athletes. He is also a vice president of the Long Island Affiliate of the national Foundation for Fighting Blindness.

In 1996, as he became more involved with the Foundation, Mr. Shapiro decided to plan his own fundraiser for the organization. After recruiting 12 wine distributors, he organized the first Blind Wine Tasting Gala, which raised more than \$40,000 for the Foundation. The wine tasting has since become an annual event every fall, which this year drew 550 participants.

"It is my way of increasing the awareness of the public about blindness and living with a

disability," said Mr. Shapiro, "and of raising money for the Foundation. My mission is to show people that despite the obstacles, one must continue to keep fighting, to find the right tools to enhance the quality of their lives, and to do something to make a difference."

BERT REIDEL'S FULL AND WONDERFUL LIFE

By Bert Reidel

(EDITOR'S NOTE: Following is an unusual story of a man who accepted the challenges of life as a disabled person and overcame the obstacles of losing sight and hearing - an inspiring lesson in determination and resourcefulness.)

I was born in December of 1912. At this time the medical profession knew little about the disability of Usher syndrome.

I remember the first days of my first grade in elementary school. I realized right away that

I had difficulty in hearing my teacher. Instinctively, I began to read his lips in addition to gathering as much sound as I could. However, in this early phase of mysterious symptoms that I never could understand, I got through elementary school. I remember though that I developed a habit of continually tying knots in my hair, which, I now know, was a response to the stress I was experiencing.

Then came the challenge of high school. This was even more difficult. I had to get smart and helpful classmates let me borrow their notes and, with a lot of reading of text books, I somehow got through high school. I had the support of a family which highly valued reading and getting a good education. My father was a doctor and I was motivated to do the best I could and ultimately graduated with honors and gave one of the commencement speeches.

I loved basketball but I could never be as good as the other players on the team no matter how hard I tried because I did not have their degree of physical dexterity and over reacted often on the court. I had to satisfy myself with

just earning a letter.

College again was quite a different time. The large classrooms and lecture halls were very difficult for me. Again I had to get help from other students and read my text books thoroughly because I couldn't hear the professors. But I did all right and found that I could enter dental school after completing my college courses. Today, of course, I would never have been admitted because a complete medical exam is necessary and I would not have passed the requirements. However, I worked very hard to find ways to overcome my increasing hearing and sight problems and graduated from dental school. I practiced dentistry for almost twenty years.

After ten years of practice, I went to an ophthalmologist for a routine exam. I was informed that I had retinitis pigmentosa. They did not know at the time that my ears were also involved and that I had Usher syndrome. Needless to say, I was simply shocked by this information. Being in my early thirties and having a wife and three children, I had a lot of

decisions to make.

I decided to move to the state of Maine where a considerable amount of dentistry was done making dentures and partials. This was much easier than doing the fine work of drilling and filling cavities. I wanted to extend my profession as long as possible. At age 43, I laid down my dental tools, my wife finished her teacher's training and we moved back to Illinois with four children ages four to twelve.

I attended the Hadley School for the Blind in Chicago where I learned all about Usher syndrome. This gave me the understanding and the skills necessary to succeed in life as, eventually, I became totally blind and deaf.

Looking back over my 86 years, I feel that I have been one of the luckiest people in the world. I had a loving and understanding family who helped me make every attempt to enrich my life within my limitations. It was so important to get genuine compliments. I loved music and I learned to play the piano. My father helped me so much by just asking me to play certain songs over and over. It made me

love it even more. I have quite a memory of wonderful classical music that I enjoyed when I was younger and which I can still play today. With me, it was a lifetime pursuit to maximize the little that I had. And I wanted to make sure that I focused my efforts where the real values are.

If there is one word in our vocabulary that I believe is essential both for the person with Usher syndrome and especially people who care for those with Usher syndrome, that word is attitude. It is not enough to try and make life easy for the person afflicted with this problem. Doing everything for the person also doesn't help much. The key is loving the person and treating them in a way that allows them to grow into an independent, motivated and out-going person. Of course this is difficult to do. Often people want to just make it as easy as possible on the "victim." However, the reality is that we need people who understand that and support our efforts to find ways to cope with our lives.

Providing a variety of stimulations including mental, social, psychological, physical and

musical is so critical to our development into maturity. Thus in my life the people I cherish most are the ones who helped to contribute to my independent development. When one learns to do something without adequate senses there is an inner sense of happiness.

Recently we drove up to Mt. Evans, which is a fourteen thousand foot mountain with a road all the way to the top. As we ascended, my daughter-in-law described the trip on my power brailler and responded to all my questions about the views. This gave me one of the most memorable descriptions of mountain scenery I have ever had. I felt sighted! This was happiness.

I am an avid braille reader. I find great happiness staying in touch with the world by reading magazines like National Geographic, New York Times, and Fortune plus wonderful books. Recently our neighbors who have climbed in the Himalayas and recently got up to 22,000 feet were invited to dinner and demonstrated the equipment they used in this exciting experience.

I enjoyed this so much and found, over and over, what true happiness it is to get on the same wave length with interesting people.

A proper attitude and development of a sense of independence are critical to helping a person attain their own wonderful goals. I have lived a full and wonderful life. But I am only 86 and have a lot of living yet to do.

MY HANDS

By Amanda Stine (deaf-blind) 1997

My hands are ...

My ears, my eyes, my voice ... my heart.
They express my desires, my needs --
They are the light that guides me through the
darkness.

They are free now,
No longer bound to a hearing-sighted world.
They are free,
They gently guide me.
With my hands I sing
Sing loud enough for the deaf to hear,

Sing bright enough for the blind to see --
They are my freedom from a dark silent world,
They are my window to life,
Through them I can really see and hear.
I can experience the sun against the blue sky,
The joy of music and laughter,
The softness of a gentle rain ...
They are my key to the world,
My ears, my eyes, my voice ... my heart.
They are Me.

BRAILLE ACCESS TO TELECOMMUNICATION

by K. C. Spear

Background

In 1974, I was introduced to a device that enabled a person who was deaf-blind to access the telephone. It was called a "Code-com" and could be used in several ways.

An individual familiar with Morse Code, used it to send and receive messages over the

telephone. If you didn't know Morse Code, but used speech for expressive purposes, you could dial the number of a family member or friend and, by mutual agreement, pass simple messages.

For instance, each Wednesday, I called a friend to ask if we were set to go grocery shopping at the usual time? My friend would reply by simply spelling "Y-e-s" or "N-o"; and, using the Code-com the number of vibrations provided the answer. Though primitive, this device was a tremendous asset to me, a widow, living alone with a 10-year old child.

Our ability to access the telephone was improved with the advent of a TTY that displayed one letter at a time in braille on a moving roll of paper. This device was excellent for communicating directly with a TDD user, or a similar TTY system. However, one's ability to utilize this device to communicate with non-TDD/TTY users, was contingent upon whether a local agency or organization provided a relay service.

Unfortunately, existing relay services were

only available to those living in, or near, a major city. With few exceptions, early relay services were manned exclusively by volunteers and usually operated on a limited schedule. Equally important, the number of consumers who owned the TTY braille system was limited, because few had the resources to buy one.

Two major developments greatly enhanced telephone access for persons who were deaf-blind. The first occurred in the early 1980's with the manufacture and distribution of the TeleBraille. The origin of this device can be traced to the research laboratory at the Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC), where the prototype was developed. Telesensory Systems Inc. (TSI), assumed responsibility for marketing the finished product.

The second major event occurred on July 26, 1990, when President George Bush signed into law the Americans With Disabilities Act. (ADA). Title IV of the ADA, with the effective date of July 26, 1993, required common carriers offering telephone services to the general public

to increase the availability of interstate and intrastate telecommunication services to individuals with hearing and speech impairments. As a result, telecommunication relay services were established nationwide and are required to operate 24-hours a day.

The Telebraille

The TeleBraille consists of two components: a refreshable-braille display called "Navigator," and a Telecommunication Device for the Deaf (TDD). Since it came on the market in the early 1980's, it has been issued in three successive models, each featuring a Navigator and a more sophisticated TDD. In effect, newer TDD's were developed and the older models became obsolete, terminating the production of the TeleBraille I, TeleBraille II and, just recently, TeleBraille III.

Implicitly, the TeleBraille, which retailed from approximately \$5,000 to \$6,500 per unit, had a short life-span. Realistically, this situation placed the consumer at a disadvantage for several reasons:

1. Most consumers do not have sufficient income to purchase a TeleBraille. Hence, funding sources had to be found.
2. Competition has been virtually non-existent, because the market is comparatively small.

Ironically, since the establishment of state relay services, under the ADA mandate, programs are taking root throughout the country to provide funds for the purchase of devices necessary to give individuals with hearing and speech impairments access to telecommunication. At this point, however, those of us who are deaf-blind and rely on braille access face a dilemma: What device will replace the TeleBraille?

Options for Telecommunication Access Using Braille

In my daily activities at home and at work, I rely heavily on my ability to access telecommunication. Consequently, I've made an effort to keep abreast of developments in the area of access options for braille users. In the

process, it has become apparent that, although several braille-based telephone-access systems have reached the marketplace since the advent of the first TeleBraille, each manufacturer has experienced the same problem as TSI; the all-important TDD component has been discontinued.

Logically, the solution to this dilemma lies in the need to use a braille-based telephone-access system that can be interfaced with any TDD model, or, a system that has no TDD component at all.

Based on a recent e-mail message I received, I believe that a system designed to work with any model TDD may soon be a reality. The message was from Deane Blazie, President of Blazie Engineering Inc. (Footnote 1), a man who has revolutionized braille technology through the development of Braille-and-Speak and the Braille-Lite. Mr. Blazie is attempting to modify the Braille-Lite so it can be interfaced with any TDD. In the meantime, Blazie Engineering Inc. has assumed responsibility for maintaining existing TeleBraille units, as long as

the dwindling supply of parts is available.

In the meantime, there is a device on the market called the Braillephone, version IV (Footnote 2). In addition to giving a deaf-blind user access to the telephone and relay service, providing a means to communicate face-to-face with a sighted person, the Braillephone is designed for access to most computer systems with MS DOS, Windows 1.1 and Windows-95.

This system also allows the user to type messages, or change to a braille keyboard by using a simpl keystroke. The Braillephone weighs 8 pounds and consists of a TDD and a 23-cell refreshable-braille display called the Alva Braille Terminal.

There is another option with which I have personal experience. The position I currently hold requires that I travel to different parts of California and, once a year, to the east coast. At such times, I not only need to access the telephone, but must have access to the state mainframe to record case-related data.

As a result, I travel with a system consisting of a refreshable-braille display, a laptop

computer, a special external modem with software (Footnote 3) to simulate a TDD, and an internal modem for e-mail and mainframe access. At present, this system is strictly text-based, i.e., I have not yet upgraded for Windows-95.

It should be noted that there are members of the deaf-blind community who are using this type of system with a desktop PC. Currently, however, the practice of using a computer to simulate a TDD is more prevalent among members of the deaf community.

Conclusion

The purpose of this article is to give the reader an overview of both the history of braille access to telecommunication and some insight into the current status. It is my hope to make clear that there is no reason why the rapid advances in "space age" electronics cannot be utilized to offer a range of telecommunication options to meet individual needs.

For example, there are folks who need hard-copy braille; others depend on Perkins-type

braille keys for sending messages, while many prefer to use a typewriter-style keyboard; and, persons, like myself, need a versatile, portable system for use when traveling. Summarily, there is no question that the isolation which has plagued us for centuries is no longer necessary if we receive the tools for direct access to people and information.

FOOTNOTES

1. As of July 19, 1998, Blazie Engineering Inc., owns the "Blindness Division" (product) formerly held by Telesensory Systems, Inc.
2. Braillephone is a product of Audio Visual Mart, Inc. (504) 733-1500; or 1-800-737-MART.
3. Recommended external modems for simulating a TDD are: CM04 from Phone-TTY; Intele-Model from Ultratec; and, Nex-Com 300 Modem - requires FUTURA software.
4. Recommended software packages are: FUTURA-TTY a product of Phone-TTY: (973) 299-6627 (TDD/V); FULL-TALK or WIN-TALK, products require MIC-300i

MODEM Micro-Flip: (301) 262-6020 (TDD/V); and NEX-TALK, a product of NXI Communication Inc.: (801) 466-1258.

SUCCESSFUL COCHLEAR IMPLANT

By Sam Aitken

EDITOR'S NOTE: Sam Aitken is a former HKNC student.

Sam, 53 and deaf-blind hears again!

After 15 years of being totally deaf and legally blind I can now say "Wow, I hear again." I have lived in the deaf-blind world with many challenging experiences.

Throughout my rehabilitation process, I have participated in many programs. The Massachusetts Commission for the Blind has been with me from the beginning, offering me many opportunities including participation in rehabilitation training at the Helen Keller National Center and in becoming employed as a

trade coordinator in the Foreign Exchange Department at the Bank of Boston. All this I believe, was coordinated with the help of God.



HKNC Regional Representative,
Mary Ellen Barbiasz, relaxes with
Sam in his apartment.

During these fifteen years, I have met many people and have been able to participate in life, learning, growing, and sharing my life experiences.

I found out about the New England Home for the Deaf's Thompson House, in which several deaf-blind people live independently. I eventually - and enthusiastically - relocated to the Home and have become more involved in deafness and deaf culture which I am still

learning about.

My most recent opportunity presented to me was the chance to get a cochlear implant. After receiving a lot of information and going through many evaluations over a period of several months, I decided to proceed with this opportunity, knowing the risks involved.

On June 4, 1998 I heard, "Hello Sam, how are you." I was overwhelmed with happiness!!

Right now, I continue with my training with the cochlear implant and I have begun to work more intensely in redefining my career goals. I am working towards increasing my computer skills.

I would tell other deaf-blind people that it can be so frustrating at



Sam enters Thompson House at the New England Home.

times but if they stay positive and trust in God, there are always opportunities available.

We received a letter from Krista Caudill, a deaf-blind university student who is helping to design a portable communication device.

MEET KRISTA CAUDILL

I am a deaf-blind student at University of Delaware studying for a B.S. in computer science and minor in cognitive science. I am 24 years old and am a sophomore right now.

I graduated from Wilmington Friends School in 1993. I went to Gallaudet University for the Deaf in Washington, D.C., for a year, but I wasn't too happy there, so I transferred to Delaware Technical Community College as a part-time student. Originally I was thinking of majoring in counseling, social work or some other human service field. I am still interested in those areas, but I decided to switch to computer science. This spring I was finally

accepted to the University of Delaware where I am going full-time. I really enjoy my classes - I believe that I have found my niche.

My deaf-blindness is caused by a genetic condition called Leber's syndrome. It was progressive, because I could see and hear some when I was an infant. I remember seeing some colors and my hearing loss in one ear was mild and the other moderate. I have been deaf and blind since I was 5 years old, but I still have light and dark perception and I can hear loud or low-pitched sounds.

Right now I communicate primarily by sign language. For people who don't know sign language, I usually rely on an interpreter. If I am somewhere that an interpreter can't be available, I have developed a communication book with the Braille and print alphabet and some words and short phrases. I put my finger on the letter or word to convey my messages and the person would put my index finger on the corresponding letters/words to respond back. This method of communication is OK, but very slow!

The technology of the system that we got the grant for would help me tremendously to be able to communicate with other people who don't know sign language. It would open a lot of doors for me and for other deaf-blind people. I would be able to have conversations with a group of people such as a study group. I could carry around the laptop and use the system inpublic. This would be easy for the other person, because all they would have to do is speak.

Projects I have worked on: When I was a senior in high school, I was a consumer evaluator of the robotic fingerspelling hand at ASEL in Delaware. I helped evaluate how smoothly the fingerspelling hand spelled. The fingerspelling hand was originally developed at Stanford University. Later Dr. Foulds wanted me to help with another project. We started working on putting together a speech-to-Braille and Braille-to-speech system. Its purpose is to provide a communication device for deaf-blind people with others who don't know sign

DEAF AND BLIND, STUDENT HELPS BUILD A TRANSLATION DEVICE FOR HERSELF AND OTHERS

By Jeffery R. Young

Reprinted from the Chronicle of Higher Education Information Technology, July, 1998

A student at the University of Delaware who is deaf and blind is helping to build a portable electronic translator that will allow her to communicate with anyone, even those who don't know sign language.

The research project, funded by a two-year, \$98,000 grant from the National Science Foundation, is also exploring how people who are both deaf and blind communicate, and how computers can best help them.

The goal is to turn an ordinary laptop computer into a personal translator. The computer will be equipped with a voice synthesizer, speech recognition software, and a "refreshable Braille display," a device that uses hundreds of motorized pegs to turn computerized text into Braille instantly. All of

those pieces are available separately, but the project's goal is to create a piece of software that would tie them together.

Using the device, a person who is deaf and blind could hold conversations with people by typing on the laptop, which would convert the words into speech. The other person would simply respond, and the computer would convert the speech into Braille.

"This would be a great way for deaf-blind people to communicate and not have to rely on an interpreter," said Krista Caudill, the Delaware student who is working on the project, at a presentation at the National Press Club on Thursday.

Ms. Caudill gave her speech in sign language. An interpreter conveyed her words to the audience members, and then, using a type of sign language created for people who are both deaf and blind, recited their questions back to Ms. Caudill by touching her hand. "There is a shortage of interpreters in several areas of the country, and that presents a barrier to deaf-blind people," Ms. Caudill added.

Ms. Caudill hopes to benefit from the technology as she helps build it. In the fall, she will start using a prototype of the device, which she also helped design.

The project is directed by Richard Foulds, of the Alfred I. duPont Hospital for Children in Delaware. He said that computers should supplement, not replace, human interpreters for deaf-blind people. "We are not necessarily trying to put interpreters out of business," Mr. Foulds said. The goal, he added, was "to be able to have a form of communication that would substitute for an interpreter when they are not available." Human interpreters communicate subtleties that computers miss, he said.

Ms. Caudill, who is a computer-science major, says she has already benefitted from computers and the Internet. "It's opened up a lot for me," she said. "I also met my significant other on the Internet, and we have been together almost three years now."

But not everything on line is open to her. She uses a text-only Web browser that her

Braille display can process, and some Web pages don't work properly on the browser. In fact, one of the things she can't do is check her grades on line, since the university uses a password-protection system that doesn't work on text-only browsers.

COMPUTER INTERFACE TO HELP DEAF-BLIND COMMUNITY

Reprinted from the NATIONAL SCIENCE FOUNDATION NEWS, July 1998

Krista Caudill, a deaf and blind undergraduate researcher at the University of Delaware, is helping to design a portable computer that will "speak" as she types and will translate other people's speech into Braille.

Caudill is participating in a National Science Foundation (NSF) funded project to design the system that will begin to free her and others from total dependence on sign-language interpreters in order to communicate.

In addition to designing the prototype which Caudill will evaluate extensively in the real-

world setting of her campus, researchers will study the impact on communication between individuals when a computer translates the information from one format to another, such as from the spoken word to Braille.

During such translation, errors are inevitable. The project will address many questions: How many mistakes are acceptable before communication breaks down? What happens when Caudill is talking to someone who has never used such a system? How will the users adapt to using a computer to facilitate human to human communication? Can the system be adapted to include other users - people who are deaf-blind, people with other disabilities and perhaps people who have no disabilities?

Caudill, who has been deaf and blind since she was a child, uses the Internet extensively to stay in touch with many people around the world. However, she must rely on a human interpreter for face-to-face interactions with people who do not know sign language. Since trained interpreters are costly and must be

scheduled in advance, spontaneous one-to-one conversations are difficult. Caudill has been eager to pursue a meaningful college education, but both formal education and personal interactions are frequently stymied by her complete dependence upon a sign language interpreter to communicate.

Richard Foulds of A.I. duPont Hospital for Children in Wilmington, Del., received the approximately \$98,000 grant from NSF to conduct the two-year study. The project includes Caudill and several other students to design and evaluate the system. This project was inspired by Caudill's participation in an undergraduate student design course taught by Foulds. Using a technique known as scenario-based design, Caudill and a colleague, Beth Finn, developed a conceptual design selected as a winner in the student design competition of the Rehabilitation Engineering Society.

The project will allow student researchers to construct a working prototype that implements the design concepts. The goal is to create a

system that can be used by a wide range of users.

"Computers have such potential to open doors to better communication for people with disabilities - and for all people," said Gary Strong, NSF program manager for human to computer interaction. "By understanding how computers can mediate communication, we can not only help Krista and the deaf-blind community, but potentially everyone."

Caudill is also pleased. "This system will help me tremendously," she said. "I will be able to communicate with other people who don't know sign language. I would be able to have conversations with a group of people, such as a study group, or carry the laptop and use the system in public. It will also help other people who are like me."

According to the Helen Keller National Center, more than 70,000 individuals in the United States are deaf and blind. Many thousands more have related communication difficulties.

COUPLE SEE DEAF-BLIND SON AS SOURCE OF JOY, MYSTERY

By Janet Bingham

**Reprinted from THE DENVER POST,
July 1998**

High he swings. Up in the air, down, up, legs pumping, face raised to feel the sun. Light flashes through leaves to make shifting patterns of green against a pale blue sky. The world is a silent, unfocused blur of motion. He smiles.

Sean Wenlock loves motion. He loves swinging and swimming, riding on roller coasters, bouncing on beds and trampolines. His parents watch, see the happiness, hear the swing creak heavily, chains straining. He is 18 now, 6 feet tall, and weight 110 pounds.

Sean doesn't hear or speak. He barely sees. He lives in a universe of light and dark, of hot and cold, of smell and taste and texture and touch. Some call him deaf and blind and "cognitively delayed." His parents call him their source of joy, their mystery child.

This is Sean's story, a glimpse into a unique

life that most people cannot come close to imagining.

He arrived like a guest from another world, and his parents weren't sure at first that he would stay. His mother held him just moments after he was born, long enough to see that he was much too thin. Then a doctor whisked him away. The next time she saw him he was in an incubator, tubes emerging from his tiny body in all directions. She didn't know if he would live or die.

The Wenlocks were in Denmark, where American-born Nancy and her British-born husband, Mick, were studying and working. They strained to catch the worried Danish conversation around them. Was it his heart? his breathing? Every day, Nancy reached her finger into the incubator and stroked him. It was a month before she could hold him again.

Even when the tubes were gone and Sean was home and in their arms, his parents weren't sure he would make it to the next day. If he coughed, they were at his side. It would be months before they would fully know his

situation.

Because he was born with cataracts, the lenses of his eyes were removed, leaving his vision blurred. Tests showed he was also deaf. To stimulate Sean's vision, doctors gave him baby contact lenses. He repeatedly managed to get them out. They tried glasses. He tore them off. Hoping he might have some residual hearing, they fitted him with tiny hearing aids. He pulled them off.

Otherwise, locked in silence, able to see only blurred shapes and colors, Sean seldom moved. Other babies began to lift their heads, sit up, crawl. Sean just lay there. The one thing he did do was smile. He had a smile that radiated. It filled the room.

Then one day he giggled. He giggled and chirped. Nancy and Mick would hear his contagious giggles and start laughing. It was the mystery of Sean. What was it that made him smile and laugh in his silent world?

His smile and his laugh kept his parents going through the months and years when he didn't do any of the things other children his

age did. He didn't stand or walk until he was 4. But he smiled and giggled.

That kept them going even when he went through a stage of beating his head against the wall and floor, biting his hands, slapping his face until it was bruised, and pinching and scratching and hitting those around him. Sean, they learned, is 100 percent - 100 percent angry or 100 percent happy. Always they sought to crack the code, to bring back that radiant smile and those giggles.

Sean stops the swing. He knows his way around the yard of his east Denver home and finds the sprinkler faucet, which he turns on before his mother can stop him. He loves the feel of the water, the reflections of spray in the sun. But he can't see well enough to know that the hose has been moved and is now spraying the drying laundry on the other side of the house.

Nancy laughs, helps him sit, and hands him a broken twig. He sniffs it, twirls it between his fingers, feels its knobbiness, breaks it in half, drops one piece, twirls the remaining piece. He

discovers the line in the grass that divides sunlight from shadow and moves his head back and forth, feeling the difference, heat and coolness, light and dark.

Sometimes, late at night, Nancy sits at her computer and tries to write about Sean. "If I stop to think about what it must be like, locked into a body through which he cannot speak, cannot hear, cannot see anything but a blur, it can bring me to tears...if I stop to think about it. He is ALWAYS on the go."

It was when a friend bore a deaf child that Nancy remembered the rubella outbreak at the day-care center their older children attended. Nancy had kept her 3-year old son, Chris, home for a day and doesn't recall being sick, but she had been two months pregnant with Sean. Rubella, especially if contracted in the first three months of pregnancy, can cause birth defects.

At first, his parents were too busy to worry that their son was not destined to become a doctor or a computer engineer or even play soccer with his dad. They were just glad he was

alive. They were happy when he could walk. Nancy at age 8 had played the role of Helen Keller in "The Miracle Worker." She knew well the story of the deaf and blind girl and how her teacher, Anne Sullivan, helped her learn sign language, speak, read and write in Braille, and eventually go to Radcliffe College and graduate in 1904 with honors.

But unlike Sean, Helen Keller had crucial exposure to language before a brain fever destroyed her sight and hearing before she was 2. Sean at age 18 doesn't know as many signs as she did at 10, but he can communicate - by pulling, pushing taking someone's hand, putting it on what he wants.

Mick helped Nancy re-cast her thinking. "Sean doesn't think he is lacking," he told her. "He doesn't know he is deaf and blind. His world is his world. His handicaps or disabilities are in our eyes, not in his. He is just aware of experiences as he goes through life. Sean must think we are the most incompetent people around. He does try to communicate. We just can't understand him.

"Sean is upset. He slaps his face lightly, bites the back of his hand. Is he sick? Dehydrated? Hungry? Too hot? Too cold? Are his shoes full of gravel? Or is he just bored."

He signs for "drink," but Nancy knows this is his universal sign for "I want...." Nevertheless, she brings him a tall plastic cup of Gatorade. He drinks and flaps his hands. "Flappingly good," interprets his mother. He drinks up to six quarts of Gatorade a day. Foods were his gateway to communication. Some of the first signs he learned were for foods. With his highly developed sense of smell and taste, Sean is a gourmet. He loves sauteed mushrooms, vegetables, vindaloo curries, quality ethnic dishes. Like a wine taster, he sniffs the aroma of each dish. He turns up his nose at Crackerjack, bacon, french fries and carbonated drinks.

Water was another gateway. He likes to fill his bath with hot water, balance on the side of the tub in the steam and wait for it to cool. More than anything he likes to swim. Before he began moving around in his crib, he could move

around in the therapy pool at his Danish special education pre-school. When he was 7, Mick taught him to swim. Actually, Sean taught himself to swim. Mick stood in the pool and watched in amazement, day after day for several weeks, as Sean explored the water, venturing away from the safety of his father, then coming back, then venturing farther.

In the water he was free, no longer tripping awkwardly over objects he couldn't see, but graceful, fluid, turning somersaults, floating on his back, even seeing better underwater. He played games with his father, zipping toward him like a torpedo and hugging him.

One night shortly after Sean learned to swim, his parents awakened to the crash of plate glass. Fearing a burglary, they ran into the living room, only to find that the glass had been broken from inside. They rushed to Sean's bed. No Sean. Outside they heard giggling and splashing in the pool. Sean, in his pajamas, had crossed the parking lot to the apartment swimming pool. They found him in the water, happy as a clam. They had discovered how

much he could do when motivated.

So many things brought his smiles: swinging in a blanket, pillow fights with his brother Chris, rays of winter sun on his face, hugs and kisses from his family. So a few years later when he began head banging, pinching and hitting, they knew there had to be a way to reach him. The head banging began when he was about 11, after the Wenlocks arrived in Denver. In Denmark, Sean had spent nearly two years in a residential school where he had learned to recognize 30 to 50 signs. The Danes use a different sign language, and there was no way to explain to Sean why the signs his American teachers used didn't make sense.

The Wenlocks had trouble finding any program for him at all. Most schools, including the residential Colorado School for the Deaf and the Blind, were organized to educate those who were either deaf or blind, but not both. Sean's behavior also was a concern: His parents had scratches on their arms and some of Sean's aides were afraid of him. Mick also had started a second job so Nancy could stay home full

time. She took Sean for various evaluations and found a private tutor to help him learn some American Sign Language. She also found an expert who followed him for a day and determined that he was clever enough to communicate his needs differently to different people.

Finally, Sean was enrolled in the Margaret Walters School for students with developmental disabilities. At the Jefferson County school, Principal Ron Marquez connected Sean with Laura Castens, the 5-foot-2 teacher assistant who has been with him now for six years.

Castens painstakingly learned to reach Sean by entering his universe. Gradually, he responded. His parents had prepared him for swimming by holding his swim trunks under his nose. The whiff of chlorine told him fun was about to happen. At school, Castens introduced other objects to represent activities: a terry cloth wrist band for gym, a piece of chain to represent swinging, a comb for hygiene, a spoon for home economics, a piece of seat belt for the trip home. These she put in

a fanny pack that he could wear. At the same time, he learned the American signs for these activities.

As his options for communicating increased, the head banging decreased and he began to learn new things. He helped hang clothes for the Jefferson County Action Center, collated papers for St. Joseph Hospital and operated a crusher for recycling pop cans.

A friend who owned an old and placid horse let Sean ride. He loved the feel of the horse under him. The patient animal would stand still, no matter what, while Sean tried all the various ways to balance. He would feel the horse's front leg with his out-stretched arms. Then he would lean over the other way and feel as far down as possible along the other front leg. He would lean to see how far he could go and plop - land in the sawdust. His giggling could be heard all over the barn. Then his hand would feel for the saddle horn, he would get his foot back into the stirrup and he'd climb right back on.

Once, he climbed on backwards. He felt the horse's rump, leaned over that way, and slid off

the back as though on a sled. Again he lay in the sawdust giggling, then got up and climbed back into the saddle. Nancy wrote in her journal, "He could never have explored those options, found out the consequences, or discovered the relation between cause and effect, had he not been able to experiment on it himself in an undisturbed fashion."

One day at home, there was another breakthrough. Nancy looked up to see Sean coming through the door, clearly agitated and repeatedly touching their dog Clancy's head. This in itself was startling because Sean and the dog, a big yellow Labrador, had never paid much attention to each other. Sean was telling her that Clancy had stolen his lunch.

It was a little thing, but for Nancy it marked a turning point. It meant that Sean was aware of the dog and had clearly communicated distress without banging his head or hitting. While Sean continued to appear isolated and alone around people he didn't know, he expanded his repertoire of ways to get the attention of those he loved. Sometimes, if his

mother was reading, he would gently take the book out of her hands.

If his father was busy at the computer, he would lift his hands off the keyboard. He played mischievous jokes, pushing a glass full of milk very slowly to the edge of the table just to see if anyone was watching.

The Wenlocks continued to seek the things that motivated him. With the help of Denver Options, a nonprofit agency, they bought the adult backyard swing and membership in a community association that runs a pool. Denver Options also helped this year with summer stipends to pay two college students who take turns being Sean's aide at a day camp for disabled young people. The two students took a genuine interest in him, and Sean reciprocated.

One of the students took him on his first trip to Elitch Gardens amusement park. As the Twister, the fiercest roller coaster, topped the first rise and started its plunge down. Sean grabbed onto his companion's neck with one hand and pulled his shirt over his head with the other. He kept his head covered for the entire

ride and looked a bit pale as he stepped out. But without the least bit of hesitation, he followed his friend on to another ride.

Sean in still life: He sits on the swing seat, motionless, studying a small pebble in his hand. He rolls it back and forth between his fingers, turns it over and around, feeling its texture. He likes smooth stones and rough stones and feathers and leaves and sometimes will spend hours with something small in his hands. His father comes over. Sean seems to sense his presence before he gets there - he greets new acquaintances by sniffing their hands. He rises, puts his arms around his father's neck, his face is at peace and it is as if the two are having a conversation.

Mick and Nancy think more these days about what will happen as Sean - and they - get older. Who will one day care for him, when they no longer can? A complicated tangle of concerns over citizenship and the availability of residential care centers makes the future uncertain. Nancy is the worrywart. Mick says the most important thing they can do is let Sean

know he is unconditionally loved. Nancy agrees.

She thinks that if she ever writes a book about Sean it will be funny. None of this "victim" stuff. For in the end, it is not the "problems" they think of when they think of Sean, their mystery child. "He has given us such pleasure, so much sheer fun," Nancy says. "There is lots of joy in this child."

Sean is swinging again. His face is turned to the light.

GOING FROM DEBT-RIDDEN TO DEBT-FREE

By Christine Dugas

Reprinted from USA TODAY

James and Alice Turner have overcome enormous obstacles to become financially independent.

James was born deaf and diabetic. Alice, deaf since age 4, is also now blind. The couple met at the Alabama School for the Deaf. They married and moved to Atlanta. In 1975, Alice

gave birth to their son Jamie, who has normal hearing. At 30, Alice was diagnosed with retinitis pigmentosa, a disease that slowly causes blindness. Six years later she was legally blind.

The Turners ran into financial trouble after James was laid off from his job at a printing company in 1986. They lived off of their savings as long as possible. But by 1993 they could no longer keep up with their medical bills and credit card debt and began to consider filing for bankruptcy.

James asked a friend to refer them to a bankruptcy lawyer. Instead, he recommended that the Turners go to the Consumer Credit Counseling Service (CCCS) in Atlanta. "We didn't want to file bankruptcy," Alice said through an interpreter. "Once we found there was another alternative, we went to Consumer Credit Counseling."

At that point, the Turners owed more than \$9,000 and were living on Social Security disability payments. Through CCCS, they began a debt-repayment plan. It allowed them to make one monthly payment to CCCS. The agency,

which often can negotiate reduced or waived finance charges, distributes the money to creditors on behalf of clients.

James and Alice were determined to make their monthly payments to CCCS. So when their car needed repairs that they couldn't afford, they gave it to their son. After that, James had to rely on friends for transportation or walk a half-hour to the bank for money orders.

"When our house needed repairs and we didn't have the money to pay for them, we asked for help," Alice said. Habitat for Humanity agreed to fix their home at no cost.

Last year, after 3 1-2 years of working with CCCS, they were finally debt-free. Alice now works part time for the Georgia Sensory Rehabilitation Center. In addition to diabetes, James has prostate cancer and is unable to work. But they are saving money and helping to pay for Jamie's college education.

This week the National Foundation for Consumer Credit (NFCC), the umbrella group for more than 1,500 nonprofit consumer credit counseling offices across the USA, selected the

Turners as the graduate clients of the year.

"Many people - even without the barriers the Turners face - would have given up long ago, but James and Alice picked up the pieces and got their financial lives back on track," says Durant Abernethy, NFCC's president.

THE SCATTERED FEW

By Samuel Campbell

(The author has Usher syndrome II)

My tunnel vision has no end
My hearing slowly fades away
I have no power to extend
The ticking clock, the light of day;
I'm losing sight and sound.

The voices of a billion tongues
The vision of a rainbow, lost!
I clench a fist and fill my lungs
And scream "I'll never pay the cost
Of losing sight and sound!"

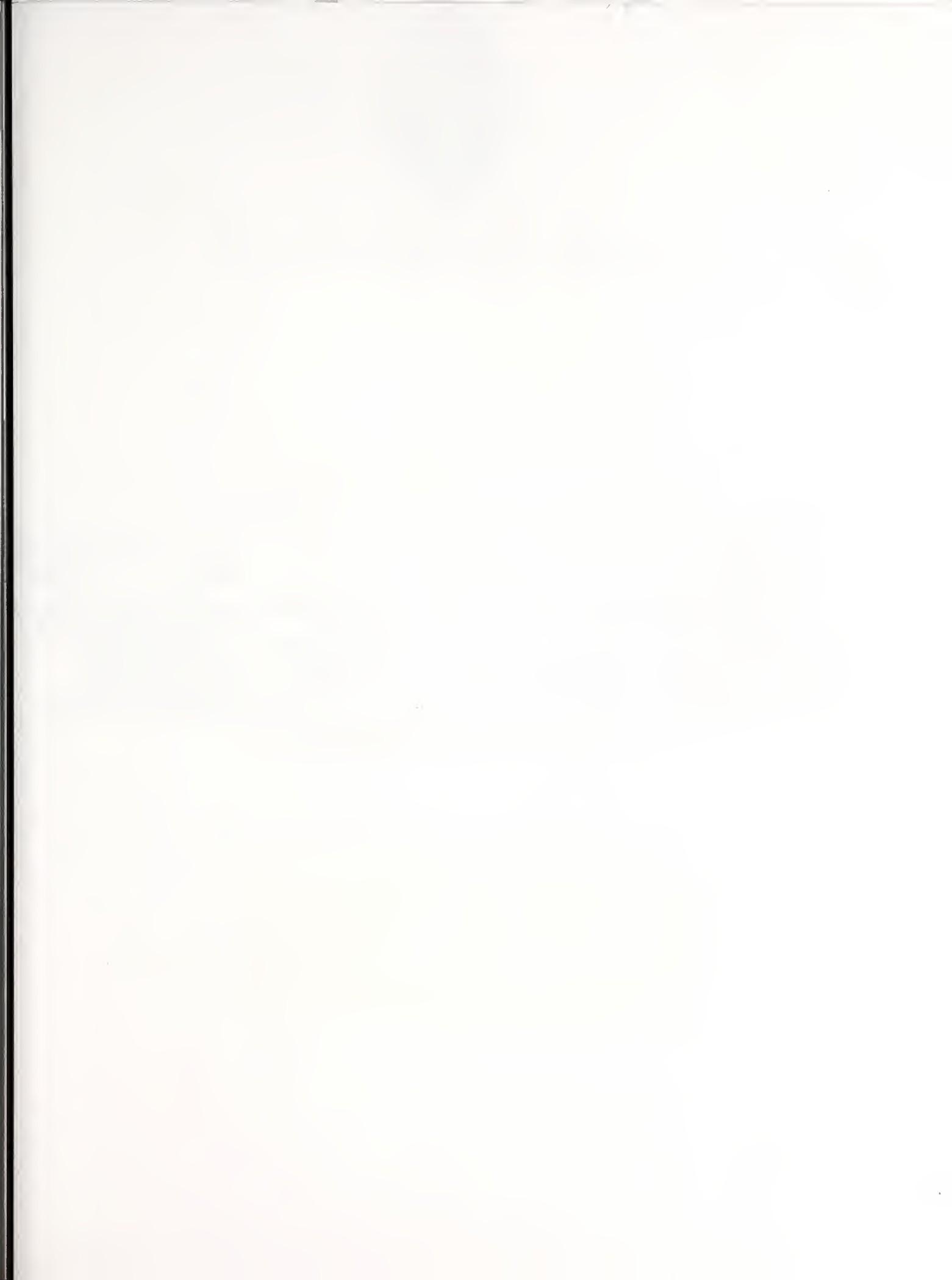
But shadow falls and darkness looms
And silence creeps in crowded rooms.

My image in the mirror moans
I face another fearful night.
I dread within my weary bones
To contemplate this awesome plight
Of losing sight and sound.

I know that others share my thoughts
And share the raw emotions too--
They live in crowded, lonely spots
But where are all the scattered few
Losing sight and sound?

Did Helen Keller feel the same?
Does God in heaven know my name?

Perhaps they see us from afar
As passioned souls in flesh and bone
Or fragments of a broken star...
I only know I'm not alone
In losing sight and sound.



NAT-CENT NEWS

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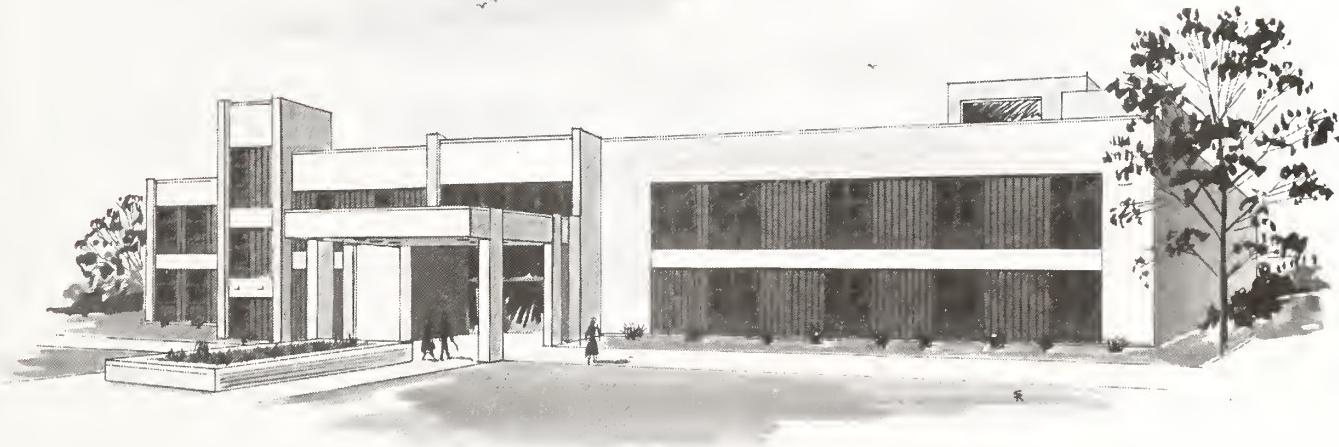
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SUSAN J. SPUNGIN, (NC-AD)
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EDITORIAL: CONSUMERS' INPUT NEEDED

By Robert J. Smithdas, LHD, Litt.D, LHD

Today we live in an age of fast-paced technologies which are developing assistive aids and devices that are adding new dimensions to the way disabled people live and achieve greater independence and self-reliance. High tech has already provided the deaf-blind population with telecommunication devices, access to a world of information via computers and refreshable braille displays, and signalling systems that let them know when the telephone or doorbell rings.

In many cases the assistive products used by deaf-blind people at the present time are modifications or adaptations of products used by blind or deaf people. For example, signalling systems are adapted to transmit coded messages or signals by vibration, instead of lights that flash for the sighted deaf; and the Enhanced Noteteller, a device for indicating the denominations of paper money has been adapted

to use coded vibrations to distinguish bills, rather than having a synthetic voice announce the amounts, as the original device does for the hearing blind.

There is nothing wrong with such changes to adapt such devices; in fact, it is commendable that efforts are made to accommodate deaf-blind users. But to be realistic, we must realize that most of these products were not originally designed for use by deaf-blind individuals and often lack features which would benefit deaf-blind consumers.

I was present at the first showing of the TeleBraille, developed by TeleSensory Systems back in the early eighties. The prototype was very different from the current models in use: by flipping a switch, one could change the machine from telecommunication mode to face-to-face mode. It was a single machine, smaller than the present TeleBraille models which have a braille box and a telephone device for the deaf (TTY) joined together. And it was much more portable than the TeleBraille models which weigh about fifteen pounds when packed for

travelling.

Research and development of special assistive devices for the deaf-blind will undoubtedly always be hindered by the fact that the deaf-blind population is relatively small compared to other groups of the disabled, and that such a small market precludes any ongoing profit for manufacturing such devices.

Originally, Helen Keller National Center developed the basic concepts which eventually led to the development of TeleBraille and the first wireless signalling system for residential use; but lacking essential funding for manufacturing and with no qualified personnel for production, the projects were turned over to TeleSensory Systems and Sonic Alert which refined and produced them.

It is probable that modification and adaptation of existing assistive devices for use by deaf-blind individuals will continue to be the chief means of providing devices to meet their special needs for information, communication, and employment.

It is important for deaf-blind people -

individually and as a group - to express their wants and needs and bring them to the attention of potential providers who can supply useful technical assistance.

FIELD NOTES

By Nancy Flax, Director, HKNC Field Services

Field Services has two new staff members to announce. The first staff member I would like to share with you is Cathy Kirscher. Now many of you may say, "I know her," and yes, many of you do know Cathy.

Several years ago Cathy was the regional representative in Region Ten and she had attended many of the AADB conferences as a team leader. She had assisted with both the Support Services Provider (SSP) program and interpreters. During the last few years, Cathy has been with our Affiliate Program in San Diego - the California School of Professional Psychology. The Affiliate Program did not want to see her leave, but she is still in the

field.

Cathy has returned to working directly with field services as our regional representative for Region Nine, which includes Arizona, California, Hawaii, Nevada, Guam and Samoa. She has been busy moving the office to San Diego and visiting with individuals in Arizona, California, and Hawaii. Cathy brings many skills and experience to the position. HKNC is lucky to have her back as Region Nine's representative.

The second person I want to share with you is Amy Parker. Amy will be working with us to start a new position, the Community Placement Specialist. Her primary work area will be in Region Five. This region includes Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin. This is a big region with a very large population, many affiliate programs, and other strong providers of services for individuals who are deaf-blind.

As many of you know, Laura Thomas is the regional representative in this area. Recently, Amy worked with HKNC staff in a semester

long internship, the focus of which was with the case management staff and students. When her internship ended, we regretted to see her return to Tennessee to finish her master's degree. Upon hearing about the new position in Region Five, Amy decided to apply. She will soon be finishing her degree and making the big move to Illinois where she will share an office with Laura Thomas.

Amy's initial emphasis will be to work with Laura and students returning from their training program at HKNC, community and family members, and Center staff to ensure that these individuals participate in the employment, housing and community activities they have been striving for. We also expect Amy to become involved with former students and other residents of the region. Region Five will certainly have a power force in action.

You may have heard about the federal government's emphasis on outcomes. This new emphasis is the result of the Government Performance and Evaluation Act, frequently referred to as GEPA. This past February all of

our Field Service staff met at the Center with the supervisors and a consultant to learn more about performance and evaluation. One of the areas we want to strengthen is our follow-up services, and Amy Parker's new position will be part of this process.

**HELEN KELLER DEAF-BLIND
AWARENESS WEEK:
CONSIDER HIRING A SKILLED AND
HIGHLY MOTIVATED
EMPLOYEE - WHO IS DEAF-BLIND**
By Barbara Hausman, Director, Public
Relations Department, HKNC

SHARE HELEN KELLER'S VISION by participating with agencies and organizations worldwide in the Helen Keller National Center's (HKNC) 1999 Awareness Campaign which focuses on the Employment of People Who are Deaf-Blind who are skilled, highly motivated, hard-working and reliable employees.

This year's campaign features a young married woman, Cindy Gagnon, who was born

deaf-blind and has mild cerebral palsy. She works full-time assisting with floral design and package assembly at one of the retail shops owned by the world's largest florist, 1-800-FLOWERS.

**Cindy can give you
many reasons why
people who are deaf-blind,
like herself, should be
given a chance to work.**

But not right now.

**She's busy filling a
customer's order.**

1-800 FLOWERS is proud to employ Cindy Gagnon. She is one of hundreds of skilled deaf-blind people employed at corporations such as the Gap, Hewlett Packard, Avis, and Pizza Hut as assemblers, computer/data entry personnel, and food service workers.

If you have job openings and would consider hiring a person who is deaf-blind, please call the Helen Keller National Center and speak with the vocational coordinator at 1-800-255-0411 ext. 300.

Share Helen Keller's Vision



After completing a year's training at HKNC, she moved to a supportive residence where she met her husband. They live in their own apartment, and Cindy shops, cooks and cares for their home. Though she was an independent traveler, she had to learn a new route to work, including boarding a bus and crossing seven streets.

Isaiah Brown, 1-800-FLOWERS district store manager, said, "Cindy doesn't goof off, she's on top of her work and sometimes I think we're too slow giving her assignments. She's part of the TEAM here, no one sees her as deaf-blind and everyone communicates with her."

When asked about her job, Cindy smiled and replied, "I like it very much. I pack the flowers. I make good money here, and I like my boss."

The unemployment and underemployment of America's citizens with disabilities remain an ongoing problem, according to a Training Resource Network newsletter (Dec.'98/Jan.99). Data from the US Census Bureau, FY 1996,

indicates that less than 33% of adults with disabilities were in the labor force. Also, a large gap in earnings exists between the median monthly wages of people without disabilities and workers with disabilities.

Fifteen years ago, people with severe disabilities, such as deaf-blindness, were considered unemployable. "Providing support to individuals with disabilities in community employment has produced tremendous success for many," notes Kathy Mezack, HKNC vocational services coordinator. "The growth of supported employment has been unprecedented the past few years. Starting with only a small number of people in the early '80's, approximately 150,000 individuals previously not given a chance at any job, now hold one. A 30-year study by DuPont found that loyalty is high and turnover rates are low among people who are disabled. Eighty-six per cent of employers say that the attendance of these workers is above average. Today, more deaf-blind people are receiving educational and vocational training in preparation for

employment. We know that matching an individual's work skills and preferences with the proper job is critical in achieving mutual success for employee and employer, and building a career is a personal choice. But, outdated organizational, societal and employer attitudes and policy barriers still limit employment, not the capacities of deaf-blind people. Like Cindy, deaf-blind people do work at a host of jobs from computer/data entry to food service, teacher, retail clerk, attorney, electronic assembler, chef and more."

Originally proclaimed by Congressional resolutions and Presidential signature 15 years ago, awareness activities and events featuring information about significant vision and hearing loss, or deaf-blindness, now occur throughout the year, beginning in June, the month of Helen Keller's birth date.

All citizens, health organizations, civic groups, libraries, schools and agencies are encouraged to plan state and local activities during the month of June, and especially during the week of June 27 - July 3. A sample

proclamation, a radio public service script, list of activities, 1999 poster, ad slicks, and this press release are available at no cost from the Public Relations Department, Helen Keller National Center, 111 Middle Neck Road, Sands Point, NY 11050, or by calling Barbara Hausman, 516-944-8900, ext. 325 (Voice), 516-944-8637 (TTY), faxing 516-944-7302, or e-mail: hkncpr@aol.com.

IN MEMORIAM: LOUIS J. BETTICA

Louis J. Bettica, a former associate director of the Helen Keller National Center for Deaf-Blind Youths and Adults in Sands Point, NY, passed away Thursday, February 18, 1999, after a long illness, at the Columbia Green Long Term Care Center in Catskills, NY. He was eighty-three.

Born in Brooklyn in 1915, Lou - as he was affectionately known to his friends - began his long career of service to the blind and deaf-blind at The Industrial Home for the Blind

(IHB) in Brooklyn (now Helen Keller Services for the Blind) as an assistant foreman in its workshop program. When his younger brother, Vincent, who was in charge of a newly formed program of services to deaf-blind persons, died of leukemia in 1946, Dr. Peter J. Salmon, IHB's director, appointed Lou to take his place.

In 1953, he became director of the Ann Sullivan Macy Services for the Deaf-Blind, a pioneering project to evaluate the causes of deaf-blindness and the needs of deaf-blind citizens.

Visually impaired himself, Lou was keenly interested in low vision aids to improve conditions for the partially sighted, and in the early fifties, together with Dr. George Hellinger, an optometrist, established one of the first low vision training programs in this country. When the Helen Keller National Center was established by Congress and became active in 1969, Lou was made assistant director and later was promoted to associate director. In 1967, the American Association of Workers for the Blind (AAWB) presented him with its Ann

Sullivan Macy Award for his outstanding service to deaf-blind people.

A long-time resident of Woodside, Long Island, Bettica moved to Phonecia, NY, after his retirement and his wife's death.

A staunch fan of the old Dodgers baseball team when they played for Brooklyn, Lou was also an avid fisherman who encouraged deaf-blind men to join in a deep-sea fishing club. He also organized a group of devoted volunteers who made it possible for deaf-blind individuals to participate in recreation, including trips to historic sites such as Cooperstown, NY, Franklin D. Roosevelt's family home at Hyde Park and the White House in Washington, D.C.

He was chosen to teach the actress Patty Duke the manual alphabet for the deaf and to coordinate sign language for the well-known film, "The Miracle Worker."

Lou is survived by his son, Richard, an officer in the Nassau County Police Department and a daughter, Denise Ricciardella of Phoenicia, NY; two brothers, Rudolph and Joseph; and six grandchildren.

A Mass was said at the Church of St. Francis de Sale, February 20th, followed by burial at St. Francis de Sale Cemetery, Allaben, New York.

DEAF-BLIND STUDENTS LEARN MARTIAL ARTS AT HKNC

By Emily Berkowitz

(Reprinted from the Port Washington News,
Port Washington, NY)

The line of martial arts students, both male and female, all dressed in white gi or uniforms, respectfully bowed to their instructors. After kicking and punching exercises, they were paired for one-on-one grappling, or ground wrestling. On the floor mats, the students rolled, arms gripped around each other, their faces registering their determination. Grunts, exclamations and laughter filled the air. Their beaming faces revealed pride and satisfaction. They rose again and again for a new match or a rematch. And yes, these athletes are all deaf and blind, or have some degree of vision and

hearing loss. All are students at the Helen Keller National Center (HKNC).



Instructor Igor Chernyakov and HKNC student Brandie Young demonstrate the wrist grab technique. Interpreter Jim Belanich gives tactile cue.

This pilot program of teaching martial arts to deaf-blind or those with varying degrees of both impairments, is a unique collaboration. The nonprofit National Sports Training Foundation, established by martial arts champion, Tokey Hill, and HKNC joined together in this highly beneficial venture. Lisa Bennett of the Sports Foundation and the project

coordinator, explained the genesis of the groundbreaking program. Coach Hill, long involved in offering karate and self-defense programs to physically challenged and underprivileged individuals, was approached recently by a parent of a deaf-blind child. She asked whether her child's self-confidence could be improved through martial arts. Accepting this new challenge, Coach Hill began to envision developing a special program.

Maricar Marquez, HKNC's recreation specialist, began to consider the same possibilities as well. Center students regularly use the community's gyms, including the Eastcoast Athletic Club, which is home to Tokey Hill's Karate Center. The interest of one HKNC student sparked her own, Maricar explained, and thus began the consideration of bringing a special martial arts program to HKNC and integrating it into the recreation curriculum. The idea became a reality and over the past two months, the Tokey Hill Karate Center instructors have conducted weekly classes in martial arts at HKNC. The program

is about 70 percent grappling, and 30 percent karate.

Enhanced physical and emotional well-being for the participants seemed to be 100 percent, which was a major goal of this innovative program. This population, it was explained, can feel especially vulnerable, without all the environmental cues to alert them to risky or potentially dangerous situations. But this changed as their training progressed. Lisa Bennett observed the students' confidence soaring and their pleasure obvious as they learned and practiced martial arts techniques. Now, their delight and self-assurance were unmistakable as they demonstrated what they had learned.

As instructor Chernyakov gave verbal orders, sign language interpreters unobtrusively used visual or tactile sign language to inform the students, who eagerly engaged their opponents, trying to pin them to the ground, or fend off an attack from behind. The women of the class, Chernyakov added, especially love to compete. "I have gained tremendous confidence in my

own ability to defend myself," one student explained. Another student, Wendy Feliz, stated that "I've learned how to protect myself, and I've gotten physically fit." She added emphatically that "it really is a lot of fun" and advised others to "take it up as a recreational activity and to increase self-confidence."



Hon. Master of Sport, Sambo USA Igor Chernyakov, instructor, front, explains a new method of self-defense, a grappling move. Angela Lampiris interprets for HKNC student Richard Putt, who has some residual vision and is deaf. Jim Belanich uses tactful sign language to interpret for HKNC student Brandie Young, who is deaf-blind.

Yet greater self-confidence and self-reliance are not the only goals of this program. Coach Hill envisions making this program nationally available at appropriate martial arts schools across the country, "wherever the deaf-blind individual lives," Lisa Bennett added. Moreover, Coach Hill, who is head coach for the U.S. National Karate Team, hopes to create opportunities for athletes who are deaf-blind to qualify for the first US National Team in martial arts.

Though new, the pilot program demonstrates a guiding HKNC and Sports Foundation philosophy that barriers can be eliminated or overcome. Everyone has obstacles in his way, Chernyakov stressed. Watching the students grapple on the mats was a clear reminder that such obstacles can be overturned.

Further information about the program can be obtained by contacting Tokey Hill at (516) 625-9695 or the Helen Keller National Center at (516) 944-8900 Ext. 325 (Voice) or (516) 944-8637 (TTY).

LIFE AT THEIR FINGERTIPS

by Barbara Hausman, Director, HKNC Public Relations
(Reprinted from North Shore Magazine,
Manhasset, NY)



Bob, along with Michelle, displays the Migel Award Bob received from the American Foundation for the Blind in 1995.

"We've been married for 23 years - GOOD years," a radiant Michelle Smithdas told Barbara Walters during their recent 20/20 TV interview. She and her husband, Robert, own their own home in Port Washington and both work at the Helen Keller National Center. Michelle teaches braille as an instructor in the Communications Department and Bob is a director and head of the Community Education

Department. She received her master's degree in Education of the Blind and Visually Impaired from Teachers College, Columbia University, in 1989. He earned his master's degree, with distinction, in Vocational Guidance and Rehabilitation from New York University in 1953, and is the recipient of three honorary degrees and dozens of prestigious awards. Nothing unusual, except that both are deaf-blind.

At the age of 4 1/2, Bob lost his sight and hearing due to spinal meningitis. His formal schooling began at Western Pennsylvania School for the Blind, continued at Perkins School for the Blind in Massachusetts, from which he graduated with a scholastic average of 98.6. He entered a training program at The Industrial Home for the Blind (IHB) Brooklyn (now Helen Keller Services for the Blind) and received a fellowship to St. John's University. With the help of a devoted interpreter/aide, he graduated cum laude in 1950. While employed at IHB, he played a key role in developing congressional legislation which established the Helen Keller

National Center for Deaf-Blind Youths and Adults (HKNC). He honed his professional skills as associate director of Services for the Deaf-Blind, lived in his own apartment and bucked the subway system each day.

Confident and self-assured, with a quick wit and definitive opinions, Bob is a man of many gifts. He was honored as Poet of the Year by the Poetry Society of America in 1960, and is the author of two collections of poetry, "City of the Heart" and "Shared Beauty" as well as his autobiography, "Life At My Fingertips," recently updated and soon to be published. He is a prolific reader and subscribes to some twenty braille magazines a month and several newspapers.

The most dynamic event in Bob's life occurred when he received a letter from Michelle Craig in 1972. One of nine children, Michelle was born hard of hearing and became profoundly deaf at age 15. She was enrolled at Gallaudet University in Washington, D.C., was president of her sorority and active in campus life, when she lost her vision after a snowmobile

accident during her senior year.

Reaching out for help after this devastating and traumatic loss, Michelle was encouraged by Bob to leave her family in California and come to HKNC for vocational rehabilitation training. Ultimately, she realized that if she wanted to accomplish anything, as a deaf-blind woman, she needed to learn tactile sign language, master braille, learn mobility techniques, and acquire independent living skills such as cooking, sewing, banking and more.

Bob and Michelle literally bumped into each other on her first day at the Center. Their friendship bloomed into a loving one and three years later they were married. Bob wrote a moving poem for their wedding:

*There is no need to speak, I understand
each quick impulsive movement of your hand.
By some strange magic of the heart I guess
the meaning of each gesture, each caress.*

*Your fingers can be gentle, firm or kind;
or fierce when anger surges through your mind.*

*Or they can trace, with such exquisite grace,
the tenderness love mirrors in your face.*

*Oh, when I reach to take you by the hand,
it is because I need to understand
that I am not alone in this broad land.*

Michelle progressed rapidly as a student and became a teacher in training and was then hired as an instructor's aide in October, 1975.

In the summer of 1993, Michelle inquired about a Cochlear Implant (CI) and decided to have this innovative surgery. The CI is an electronic device surgically implanted in the ear which processes sound. "I knew that even if I couldn't understand speech after the implant, I would be able to hear some environmental sounds, any sounds - you know being deaf-blind is very lonely," she explained.

One month after surgery, her precious implant was turned on. "At first, I was not sure what I was hearing. Then I realized it was my husband's voice. Just knowing that he was talking and that I could hear him for the first

time ever was thrilling." Today, she can hear him calling her name, she can hear a door creaking, an alarm clock ringing and a trumpet playing. She can even discern some conversation. "To be honest, I feel more alive and definitely more in contact with the world. It's rather exciting to know that there's so much noise around me!"

New technology has eased the lives of Bob and Michelle, as it has for some 70,000 other deaf-blind people in the U.S. Accessing information is now available through the use of high-tech adaptive equipment. Michelle uses a portable computer with a power braille display to prepare her reports for work. Both use a TeleBraille, a telecommunications device with a braille display which allows a deaf-blind person to communicate over the telephone. If the individual they are calling does not own a similar device, they can use the Relay Service. They dial 1-800-421-1220 and a specially trained operator relays their message by voice to the hearing person on the other end. She types that response on her Telecommunications

Device for Deaf (TDD), and acts as a bridge between the two. In turn, Bob and Michelle can receive telephone calls from hearing friends, or call the local plumber in an emergency.

Bob uses a Braille Lite, a small portable device which allows him to type notes and save information using a standard braille keyboard. Both Bob and Michelle depend upon a personal alert system called Vibra-Call. Each wears a pocket-size pager which alerts them to a telephone or doorbell ring and a smoke alarm through a set of differing vibrations. Bob is particularly fond of his miniature vibrating light probes, battery testers and timers.

Like their mentors, students in training at HKNC headquarters are preparing to live and work in the communities of their choice, as independent as possible.

In addition to their independent living, mobility and computer classes, students have opportunities to apply their newly acquired skills at a host of different jobs out in the Long Island community from food service at Pizza Hut to data entry at Avis, to flower arranging at 1-800-

FLOWERS, to laundry work at St. Francis Hospital.

HKNC rents three apartments in Port Washington where students live independently planning menus, budgeting, shopping, banking, paying utility bills, and more, while completing their training at the Center.

Life for Bob and Michelle, and thousands of other deaf-blind people has changed dramatically over the past 50 years. As we approach the new millennium, we know that education/rehabilitation training can offer the tools needed to access a meaningful and productive life. But, like Bob and Michelle, one needs courage, determination and appropriate support from others to make it all happen. For information on HKNC services, call (516) 944-8900 ext. 325.

IMPLANTS OPEN A NEW WORLD TO THE DEAF

By Sheila Anne Feeney
(Reprinted from the NY Daily News)

Sickle cell anemia had robbed Joe Ann Jackson in slow motion for all her 39 years. She was born with club feet and she never developed a solid sense of balance. She then went blind in 1981. And finally, after decades of not being able to hear well, she woke up on October 7, 1987, to find herself totally deaf.

For the next eight years, Jackson felt like an exile from her own life. She learned a kind of pidgin tactile sign language, but because she grew up in a hearing family, had married a hearing man (they have since divorced) and



had a hearing son, few people she knew could communicate with her easily. While she had learned to read in braille, news of the outside world was almost nonexistent.

Then in 1995, after undergoing a battery of tests and swallowing hers fears, Jackson received a cochlear implant, a stunning little piece of electronic equipment that is partially buried in her skull, and which connects to a beeper-sized voice processor that she carries on her belt.

"The cochlear implant is great," says Jackson, who lives with her son near Union Square in New York City. "It changed my life a lot. I feel more comfortable about myself. I can talk on the phone without using the TTY (a telephone typing device). I can call the hospital without using a relay service (in which a special operator relays information to the hearing from a deaf person). I never talked to my family through the relay because they didn't like it. The joy of hearing music again, of listening to taped books - even the TV-set audio - is indescribable."

The cochlear implant is not an amplification device, but an elegant decoder that replaces the tiny hair cells inside the cochlea - the snail-shaped structure of the inner ear that is the hardest bone in the body.

Damage to the cochlea's exquisitely sensitive hair cells is the most common cause of deafness. The implant assumes their function through a process that uses a wallet-sized computer, magnets and electrodes. (The cost for the implant, surgery, and the mapping and rehabilitation procedures to fine-tune the device's function can reach \$50,000, which most insurance plans cover.)

While experiments on implanting in both ears are under way, patients typically receive the implant in only one ear, and routinely turn that ear to the person with whom they are speaking. That's so the tiny directional microphone tucked behind the person's ear can easily pick up the sounds that travel down a cord to the battery-operated microcomputer the size of a beeper (often worn on a belt or in a backpack).

The computer filters, analyzes and digitizes the sounds into signals that travel back up to a "transmitting coil" held to the skull above the ear by a magnet. Inside the scalp, on top of the skull, rests the similarly magnetized implant. It picks up the transmitting coil's signal and transfers it along the tentacles packed with electrodes that wind all the way into the cochlea. The signals then are relayed to the auditory nerve and the brain.

But the implant itself is only the first step on the road to speech recognition and use. It is not switched on until a month after surgery. Months of "mapping" to adjust the level of each electrode follows initial activation. Children face years of speech therapy and auditory training to help them learn to process the torrent of new information pouring into their ears.

Who is a candidate for a cochlear implant? Only a tiny percentage of deaf people are physically disqualified because of unusual problems such as a missing cochlea, auditory-nerve tumors or brain lesions. But not all those who are physically eligible for an implant will

benefit equally. The patients who do "instantly best are those who had hearing all their lives and lost it," says Dr. J. Thomas Roland Jr., an assistant professor of otolaryngology and director of otology and neurology at the New York University School of Medicine.

"If they're in their late teens or 20's, and never had hearing, never had language, they are not very good candidates for cochlear implants. It's not likely they'll suddenly develop language and speech, because the neural pathways were not stimulated during critical development periods to allow easy learning," Roland says. Also, adults "who have been deaf for most of their life, and aren't aural, don't want it. Their lives are intact and full and rich."

Yet some deaf folks - especially those whose vision is impaired or deteriorating - nonetheless opt for the implant to help them hear car horns, fire alarms and other alerts, even if they have little chance of acquiring fluency in spoken language. Adults who have never heard or acquired spoken language might not be denied implants, but they have extensive counseling to

deal with what one social worker terms "expectation issues" that might be unrealistic.

According to the Cochlear Corp., a major manufacturer of artificial ears, a 1994 study of almost 5,000 implant patients showed a major-complication rate of 7.4%, including device failure. Those were complications that included facial nerve damage or required another hospitalization, revision surgery or removal of the implant.

The Food and Drug Administration has approved several kinds of implants for children as young as 18 months, but some surgeons implant in children even earlier under certain circumstances. Congenitally deaf children younger than 3 are the largest group of patients getting implants.

Many hard-line proponents of "deaf culture" have relaxed their opposition to implanting in adults, but there are still some activists who oppose implants in children who are born deaf. They say that no surgery should occur until a child is old enough to decide whether he or she wants an implant, and that hearing parents

should learn sign language to communicate with a deaf child. The rub is that if a deaf child is to derive maximal benefit from implant, early implantation is essential - the longer a person goes without a spoken language, the less likely it is that he or she will ever be able to understand and acquire one.

WHO CAN BENEFIT THE MOST

About 2.5 million Americans are believed to be deaf. Estimates place the number of Americans who are both deaf and blind at about 50,000 to 70,000, with most of them having at least a trace of one of their affected senses, says Allison Burrows, from the Helen Keller National Center. Deaf-blind people usually communicate in one of three ways: tactile sign language, tactile finger-spelling or a variation of "print on palm" - drawing letters on the palm or another body part with one's fingers.

Rubella used to be a major factor in leaving people both deaf and blind, but the vaccine for German measles has greatly reduced its occurrence in the United States. Now, Usher

syndrome - an inherited condition in which someone is born deaf or hard of hearing and begins to lose eyesight with the onset of adolescence - is often the cause of someone losing two senses.

Joe Ann Jackson's deafness - and blindness - is a rare manifestation of sickle cell anemia. Many people who find themselves both deaf and blind have had diseases, accidents or genetic predispositions that combined to take two of their five senses. Whether and how well they can speak often depends on whether they were ever able to hear.

"Many people who will not opt for a cochlear implant if they were just deaf, in fact, do opt for it when they start to lose their vision. Not because they're unhappy being deaf, but because they're losing their ability to see and need environmental input," says clinical social worker Ilene Miner, who works with deaf and blind people in New York City.

The New York University Medical Center - where Jackson got her implant - is one of the nation's major centers for the 13,000 to 20,000

implants that have been performed since the mid-1980's. Dr. J. Thomas Roland Jr. - Jackson's surgeon, and an assistant professor of otolaryngology and director of otology and neurology at the NYU School of Medicine - recalled a patient who "was left deaf, blind and handless from a mine explosion." Before the man received an implant, his wife and children had to communicate with him by spelling letters out individually on his back or thigh. The man would announce the letter; his interlocutor would tap once to indicate that he had gotten it right, or twice if he had not.

While folks who are born deaf, blind, or deaf-blind and grow up knowing nothing else may not attach great despair to their condition, those who lose a sense they depend upon can suffer the deprivation acutely. Losing two senses, can inflict a terribly painful sense of isolation and impotence. "When you're deaf and blind, you're shut off from everyone," Jackson says.

Just as hearing people often lack the patience to communicate with deaf people, deaf folks

may become impatient with newcomers to tactile sign language, who cannot keep up with their fast, fluent gestures. "Blind people don't want to be bothered with you because you're deaf, and deaf people don't want to be bothered with you because you're blind. You may have two disabilities and they only have one," Jackson says.

Since receiving the implant, Jackson claims to have lost most of her deaf friends because "they said, 'you're not one of us anymore'." To be fair, Jackson now communicates so effortlessly with the nondeaf that she has little reason to practice her imperfect tactile signing, and acknowledges, "I've become friends with more hearing people now."

Augustus William Taylor, 44, is another satisfied cochlear implant recipient, who went deaf at age 20 after a medical procedure and became blind from glaucoma and a marital-arts accident. He concurs that people who are deaf and blind are the expatriates of the disability community. "When you are deaf-blind, you're neither fish nor fowl," says Taylor, a

Philadelphian who goes by "my poet name, Rasheed."

Rasheed became an expert lipreader, but when his vision began eroding, he didn't hesitate to have operations in an attempt to restore both senses. "Silence is golden, but I have to be considerate of the people around me who are trying to communicate with me," Rasheed says. "When I was deaf, I heard with my eyes. Now the implant helps me see with my ears."

EDITOR'S NOTE: Both Joe Ann Jackson and Augustus William Taylor (Rasheed) were former students at HKNC.

SPECIAL NOTICE TO HKNC STUDENTS PAST AND PRESENT

Dear students and former students:

I'd like to tell you about a directory of current and former HKNC students I am putting together, with the idea of making it available to

you on the internet and in print. This directory will be a way of connecting and networking with other people who are deaf-blind, possibly finding former HKNC students living in your geographic area. Your privacy will be protected, as the directory will be available only to HKNC students and former students. We will use a WWW address for which there will be no link on HKNC's website (www.helenkeller.org/national) or on any other website. You will have to know the address in order to access the list.

I'd also like your feedback on the proposed directory. Do you like the idea? Are you hesitant to participate? Do you have access to the internet?

If you would like to be included in this directory, or would like to have more information about the directory, please contact Susan Shapiro, c/o the Library, Helen Keller National Center, 111 Middle Neck Road, Sands Point, NY, or E-mail: AbigailP@aol.com.

Note: Susan Shapiro is a former HKNC student and is now volunteering at the Center.

IS A CLERICAL CAREER IN YOUR FUTURE?

**By Valerie Stengel Chmela, Employment
Training Specialist, HKNC
Vocational Services Department**

Over the past ten years the Vocational Services Department has undergone many changes. We have recognized the advancements in the work place and have adapted the programs here to best suit the needs of deaf-blind consumers.

As an individualized program, we can create training opportunities that are not available in traditional training environments. The clerical work place has also gone through many changes, primarily a computer revolution. Traditional office jobs have grown beyond the scope of paper filing and manual typing into computerized information management and word processing operations. These jobs are growing at an ever-increasing rate.

The Bureau of Labor Statistics projects that positions for general office clerks will grow by

seven percent between now and the year 2010. That is 215,000 new jobs in that sector, and clerical management and supervisory positions will grow by a whopping nineteen percent to include a quarter of a million new jobs in that sector. These are two of the top fifteen occupations with the highest growth rates in the United States.

Helen Keller National Center's Vocational Services Department has provided training in access programs, word processing programs, Internet access and basic office skills for several years, but it became apparent that an integrated curriculum was necessary for students to succeed in the clerical arena.

We began by visiting 30 different office managers and employment agency staff to decide what were the new essential skills in an office environment. Then, an overview of Civil Service occupations was done. The skills that were most often cited as necessary were synthesized into a curriculum which contains thirty-four items that a student must learn in order to be deemed proficient in a general

clerical position.

Touch typing skills are necessary to all other operations and generally are taught as soon as a student identifies clerical work as a desired outcome. Generally, a typing speed of 30 words per minute must be achieved in order to secure employment, though forty words per minute are necessary for the Civil Service tests.



Val Chmela and HKNC student Wendy Feliz work on the computer in the Clerical Training Program

Skills such as Internet access, Windows 95/98 and word-processing are taught as part of

the curriculum. Word processing is generally taught using Microsoft Word as this is currently the most popular office software in use today, but the program can be tailored to fit a student's vocational choices and needs.

For example, if a student decides they are interested in working in an accounting office, they would still learn the thirty-four basic skills in the curriculum because these are needed in any office. They would also need to show the ability to touch type at 30 words per minute and have a basic understanding of the Windows environment before they would progress to the Excel program and learn the basics of spreadsheet operations.

Data entry operation is still a popular vocational choice and students can also utilize the Clerical Program to learn database operations. At times the Clerical Program can be a springboard as well. It can provide the basic typing and organizational skills that are necessary for students returning to college and has provided students with exposure to computer technology that has spurred them to further

study in technology careers.

The Clerical Program works closely with the Communications Learning Center at HKNC to assist students with English language skills, business vocabulary and interpreter issues in the work place.

How does a student know if they are proficient in a particular area? We utilize the same software as Corporate Human Resource Departments to test student capabilities on computer program knowledge, general clerical skills and typing speed. This gives the student tangible knowledge of their strengths and gives them marketable numbers to use on their resumes.

The addition of the Clerical Program enables students to gain the latest skills in an accessible environment. A recent graduate stated that their time in the Clerical Program was the toughest and most rewarding vocational experience that they have ever had.

They didn't have much time to talk though, they were taking the Civil Service test in about an hour!!

RESEARCH ON USHER SYNDROME

Dr. William J. Kimberling of Boy's Town National Research Hospital is trying to find the genes that cause Usher syndrome, the genetic disease that causes a high percentage of deaf-blindness. It is hoped that this study will lead to development of treatment for the prevention and/or cure of the disease.

People with Usher syndrome are needed for this study. Dr. Kimberling is asking those who want to volunteer to provide a family history detailing who else in the family has Usher syndrome, to provide medical records from your consulting doctor, and to donate a small blood sample. All this can be done by mail at no cost to the volunteer.

If you are interested in participating in this project, or have questions about Usher syndrome, please contact Dr. Kimberling's research assistant, Mr. Thomas Fowler at 1-800-835-1468 (V/TTY), or E-mail Mr. Fowler at boystown.org.

HERE AND THERE

Kraft Foods, the well-known company which produces several brand name products, has cookbooks available now in large print or braille. Titles available are: "Baker's Easiest Ever Chocolate Recipes" - \$10.00; "Holiday Homecoming Cookbook" - \$12.95; and the "Products Preparations Directions" - \$12.95. For more information, or to order, contact: Kraft Foods at Kraft Cookbooks, P.O. Box 8806, Maple Plain, MN 55593, or telephone 888-322-6322. Specify your choice of large print or braille.

* * * * *

The Princeton Braillists have a selection of tactile maps and drawings available. Items include: an atlas of the Middle East; atlas of North and South America; and Basic Human Anatomy. Individual state maps available include: Florida, New York, Pennsylvania, and Vermont. The state maps are \$6.00 each which

includes shipping.

For further information and prices, contact:
The Princeton Braillists, 28B Portsmouth Street,
Whiting, NJ 08659-2949, or telephone 732-350-
3708.

* * * * *

Did you know that your city, county, park district, public school and even your local transportation provider are all required by law to give you information about the Americans With Disabilities Act (ADA)? These local entities must provide ADA notices to you and other interested people. ADA notices are documents to inform people of the ADA and various local, state and public services, programs and activities, as well as your rights under the law. These documents can be obtained free from the public entities. However, many entities do not have them available. The International City/County Management Association, American Public Works Association and American Association of

School Administrators are now offering ADA notice kits to public entities. They are also available in braille, large print, cassette and computer text notices.

To ensure that such entities are available, contact your city, county, town, public school, park, transportation agency, public works provider, transportation agency and other various governmental departments in your area and let them know about your rights to receive this information. Also let them know about the ADA notice kit. Information may be obtained from the ADA Hotline at 312-640-1438.

* * * * *

Looking for the latest assistive devices and supplies? Call the Assistive Devices Center at the Chicago Lighthouse for People Who are Blind or Visually Impaired and receive a free price list. The Lighthouse sells portable recorders, canes, talking calculators, talking clocks and watches, cooking and household items, braille and large print books, games,

adaptive telephones, CCTV's and many other items. To receive the price list, call 800-919-3375.

MY COMPANION

By Celine Bush

The TeleBraille has been to me
Like opening a door
And letting in the light of day,
And ever so much more.

It talks to me and tells me things
I'd have no way to know,
What will the weather bring today,
Will it be rain or snow?

It helps me speak to people who
Are far away from here,
I speak by touch and not by voice,
It makes them seem so near.

And when I'm gone and do not know

That someone called for me,
TeleBraille answers calls so I
Can later touch and see.

And if you want for me to know
Just where it is you'll be,
Just give the word to TeleBraille
And it will be saved for me.

And TeleBraille, it goes with me
To gatherings large and small,
And it's your voice, my hearing too,
Yes, it can tell me all.

This poem was written in the early autumn
of 1997, soon after I arrived at the Helen Keller
Center.

NAT-CENT NEWS

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EDITORIAL: ACHIEVERS

By Robert J. Smithdas, LHD, Litt.D, LHD

Ever since its inception back in 1969, one of the main purposes of NAT-CENT NEWS has been to highlight the achievements of deaf-blind individuals who have demonstrated success in overcoming the limitations of their disabilities and earning their personal niches in community life. These people vary widely in family backgrounds, education and experience, skills and talents. But they share one essential quality in common that augurs well for success: a determination to meet the challenges life presents with optimism and ingenuity. For them, everything is possible until proven impossible.

With a new millennium almost upon us, it is intriguing to look back over the past forty-five years and realize the progress that has been made by deaf-blind men and women in a variety of jobs and careers. A growing number are entering institutions of higher learning and graduating with degrees; at least two have

become lawyers; and others have found places in professional careers such as teaching, computer science, counselling, and art. Kathleen Spear is a counselor in rehabilitation services in California; Rod Macdonald was one of the first deaf-blind individuals to be hired by the federal government for the Department of Labor, from which he recently took early retirement; John Boyer, trained in computer science, has established his own small business, Computers to Help People; and Richard Kinney (deceased) became director of the Hadley School for the Blind, the only correspondence school for the blind that exists to date.

Nor is a list of deaf-blind individuals confined to those who have graduated from college. Many others are employed in the labor market as computer programmers, technicians, craftsmen and small businesses. They are capable and reliable workers who take pride in their work and in being useful, productive members of society.

Today we live in a world of accelerating change. Fifty years ago many of the

opportunities now available to deaf-blind people were almost nonexistent. New technologies and methods of communication, better education and a new awareness of human potentials and skills have opened up a whole new vista of opportunities that will include deaf-blind men and women who yearn for self-expression and the chance to achieve success.

MY INTERNSHIP AT AVIS

By Dusty Bauman, Former HKNC Student
Reprinted from HKNC UPDATE, Spring
1999

It is a wet, blustery day in January as I sit in front of my office computer compiling a Project Request. My office cubicle at AVIS World Headquarters in Garden City, NY, is in the Information Technology Department. My



supervisor enters and asks, "Dusty, can you break away from what you are doing and work on this priority project request, and obtain the required funding approvals and the ballpark estimate by this afternoon? You can verify and abstract the critical information from our Info Tek and IMS systems." "Sure," I reply, "I can complete this priority for you by noon." "Great!" she responds, "but we still need you to distribute our Departmental Priority list to other staff to advise them of our weekly schedule." "No problem," I assure her, "I can complete the Priority Listing by this afternoon." "Will I see you at the Sales and Marketing Priority meeting at 3:00 this afternoon?" she asks. "Yes," I reply.

This conversation typifies the volatile dynamics that characterize the environment of the Information Technology Department. I am not typical of the work force. I am virtually blind and profoundly hard of hearing, and have never seen what I'm working on, nor seen the faces of my colleagues. I have Usher syndrome II.

Although I have been night-blind since the age of 8, I lived a normal and productive lifestyle until the age of 35, in 1988. That year, I couldn't pass the peripheral vision test to renew my drivers license. The following two years involved many eye examinations which resulted in cataract surgeries and the ultimate determination of retinitis pigmentosa, which would eventually destroy my vision.

In the 1970's, I studied Electrical and Agricultural Engineering at Ohio State University (OSU), while combining an Associate Degree in Electronics Engineering from Columbus Community College. I worked for a consulting firm doing analysis and long-term projections of rural county-based electrical power distribution systems. In 1981, I worked in OSU's Agricultural Engineering Department as an electronic technician to support graduate research activities, and later managed the department's Electronics Design laboratory until my retirement in April, 1994.

I decided to pursue alternative careers, and began a triple bachelor's degree in Computer

Science, Business Administration, and Finance. I became a consumer with the Ohio Bureau of Services for Vision Impairment and the Ohio Deaf-Blind Outreach Program. Rehabilitation and independent living training, in combination with my broad academic program, would enable me to regain my personal and professional capacities. I completed an 8-week evaluation program at HKNC in June, 1998, and returned to the Center in October to continue studying alternative communication skills and travel mobility. I began my internship at AVIS as a business analyst for project development in their Information Technology Department. I work 9:00 a.m. to 5:00 p.m., three days a week. HKNC's Employment Training Specialist Joe Sampino provided dual support as a liaison and an instructor to assist with specific job-related activities.

The tasks I perform are complex. I access the personal computer through the Hunter-Joyce JAWS Screen Reading systems with speech synthesis output. I use mini headphones or FM systems for my hearing aids to ease reception in

the noisy office environment. A Hewlett-Packard Scanner and special software converts print material into computer readable files. The TeleSensory Power Braille Display device assists screen reading and proofreading. I now have a laptop computer for meetings, with the Power Braille Display attached - both portable with rechargeable batteries - and a miniature pocket cassette tape recorder for audio and verbal notes. I label documents and file folders with a braille dymo tape labeler. When I complete my HKNC training, I will pursue a position as a business analyst in project management, in a corporate setting, and will work towards certification as a project manager.

Tremendous advances in adaptive technologies are making the possibility of working in a dynamic multi-faceted environment a reality. But, entry into higher-level professional careers remains a daunting and challenging experience for people who are deaf-blind. Confidence, courage, and hard work as well as education, rehabilitation, and work experience are needed to enter the

ever-increasing complex working environments of the "Information Age" we live in.

EDITOR'S NOTE: Dusty Bauman is currently the Information Specialist at the Helen Keller National Center in Sands Point.

JILL SPRINKLE WINS EMPLOYEE-OF-THE-YEAR AWARD

Jill Sprinkle was honored as one of Careers And The disAbled Magazine's "Employees of the Year" at an awards reception in Anaheim, California, on May 13, 1999. The awards committee selected Jill based on her contributions to the disability community - including raising the awareness of the needs of people with disabilities - and her technical and professional accomplishments. The annual awards ceremony is part of the Abilities Expo, the largest display in the U.S. of products and services for people with disabilities.

PROFILE of Jill Sprinkle. Proofreader and Compositor, Technical Information Department, Lawrence Livermore National Laboratory.

Jill Sprinkle has not allowed her deafness nor her visual impairment (Jill has Usher syndrome) to get in the way of her ability to do a great job and make a lasting contribution to the technical publications produced at our Laboratory.

Jill graduated with a BS degree in Library Science from Gallaudet University in Washington, DC. She began working at Lawrence Livermore National Laboratory (LLNL) in 1978. During her 21 years of services at LLNL, Jill has made many contributions to maintain our reputation for excellence across the nation.

Jill has applied her proofreading and compositing skills to projects in most of our major programs at LLNL, including Lasers, Energy, Defense, Environmental Protection, Chemistry and Physics. She has trained many new proofreaders and has received

acknowledgments of excellent work from everyone ranging from her peers and editors to deputy associate directors. She is known for her accuracy and her willingness to work overtime when needed. She has also taken dozens of training courses to hone her skills as a compositor and improve in other areas of career development.

Jill has received several awards for her outstanding work. She received awards 3 years in a row from the Northern California Technical Publishers Competition and this year she received their highest award of distinction for her work on the Site Annual Environmental Report.

Jill's contributions to the improvement and understanding of working with deaf employees include her participation in our Sign Language Club as the vice president for many years. She has taught sign language classes and continues to provide input and advice to the Disabilities Services Program manager on ways of improving and educating our employees. Jill is active in the planning of our annual Deaf

Awareness Week events and is always offering to help in the preparations.

In addition to Jill's professional contributions, she also is active in organizations outside of the Laboratory. Jill was recently elected as the vice president of the Northern California Association of the Deaf-Blind. Her husband, Tom, has been active with this organization for years. The two of them reside in Fremont, California.

LLNL is proud of their services for employees with disabilities and deaf employees. The Disabilities Services Program manager is a certified sign language interpreter and when she is not available, they provide interpreting services from a local interpreting referral agency. They offer training to supervisors and co-workers on how best to work with deaf people. Deaf Awareness Week and Disabilities Awareness Week events provide guest speakers on a wide range of topics every year. They offer sign language classes twice a year and have a video library for employees to borrow tapes to learn sign language. They are also

concerned for the evacuation safety of their employees. They provide vibrating alphanumeric pagers for all hearing impaired employees to announce evacuation notices in case of emergencies. They also insist on Personalized Evacuation Plans for all employees with disabilities to ensure a safe evacuation, should it be necessary.

IN MEMORIAM: LEWIS HOSKINS
By Paige Berry, Program Director/DeafBlind Services, Virginia Department for The Visually Handicapped.

Dear Friends and Colleagues:

It is with a great deal of sadness that I notify you of the death of Lewis Hoskins. Lewis passed away Thursday, July 29, 1999. His funeral was held on Saturday, August 1st in Pulaski, VA, with burial in Wytheville, VA.

Prior to his retirement, Lewis was an instructor at the Helen Keller National Center in New York. Upon retirement from HKNC, he

moved back home to Virginia where he lived in the Tidewater area. A few years later he moved to Pulaski in the southwestern part of Virginia. Lewis loved going to the AADB conventions to see all of his friends, and to make new ones. He was a great communicator. He loved learning new technology and keeping up with current events. He will be missed!



This photo of Lewis Hoskins was taken while he was employed at the Helen Keller National Center

WENDY
by Ben Williams Calgary
Reprinted from the Minnesota Deaf-Blind
Association Newsletter

We had realized that our daughter, Wendy, was hard of hearing but didn't know it was such a problem until her first grade teacher told us she wouldn't make it beyond the fourth grade.

This prompted us to take her to the Children's Hospital in Montreal, Canada, for a series of tests on her hearing. The specialist told us it was nerve deafness and nothing, such as hearing aids, would help.

Shortly after, we heard of a Chinese acupuncturist in Montreal who was having good results. An appointment and trip there resulted in learning he was honest enough to say he couldn't help.

By the time she was in the tenth grade, she had learned to lip-read on her own. When the teacher turned her back, her fellow students helped her. That year we happened to be camping next to a family where the father had

nerve deafness similar to Wendy's. He told us to get a certain type of hearing aid and to get one for each ear. We did this as soon as we reached home. We were amazed at the results.

About this time we noticed that her sight had deteriorated. She had trouble seeing at night and couldn't play badminton or golf because she couldn't follow the shuttlecock or ball. Our own eye doctor knew what the trouble was but didn't have the heart to tell us. He referred us to a specialist at the University Hospital in Sherbrooke. This doctor told us the disease was retinitis pigmentosa and that it was incurable and one might eventually lose one's sight. He said not to tell Wendy but let her continue on as before.

Wendy started working at a home for retarded children. After a couple of years, she decided to take a course at the local CEGEP in Special Care Counselling. Her marks were so good that her teachers suggested she go to university. She enrolled at McGill University and majored in psychology. At this time she had another eye test. This doctor told her she was

legally blind and arranged for her to get a white cane.

After she got her bachelor's degree in psychology in three years, one of her professors suggested she go to Gallaudet University in Washington, D.C. for her master's. Gallaudet is a university for the people who are deaf.

When we were there for her graduation, we found it strange to see a person at each corner of the hall using sign language to repeat what the speakers at the podium were saying.

Wendy learned sign language while there. In the cafeteria it was very quiet with lots of conversation going on in sign language. One day as we were walking toward the residence there was a fire drill. We watched while strobe lights came on on every floor to warn the deaf students. In Wendy's case they hooked up a fan to wake her since she might not see the lights.

Wendy's name was listed in the Who's Who of outstanding students in the U.S. in 1985.

She got a job at a school for the blind in North Carolina until the position was downsized. Then she applied for a position in

Toronto and also in Faribault, Minnesota. I could tell the person who interviewed her in Toronto didn't think she could travel there even though she had managed to get around Washington and Baltimore on her own. They were quite impressed with her background in Faribault and she was hired as a psychologist at the State School for the Blind.

About ten years ago she applied for and got a guide dog, named Darby, a Golden Retriever. He is a wonderful dog and a great friend to Wendy.

Last summer she took a computer course for the blind in Minneapolis. Among other things, she had to bake a cake, pie, and cook a turkey. She said the hardest thing was icing the cake.

We are very proud of Wendy for her accomplishments and ambition. After all, she could have stayed home and lived on a blind pension!!

HKNC AND COMMUNITY-BASED SERVICES: PERFECT TOGETHER

By John Mascia, HKNC Coordinator,
Professional Services

Reprinted from HKNC UPDATE, Spring 1999

In 1996, the NY State Commission for the Blind and Visually Handicapped (CBVH), allocated funds to enable HKNC to develop and provide evaluation and training services to people who were not in need of the comprehensive program at headquarters, but instead needed very specific training that would help them maintain their place in the local community.

Under the CBVH/HKNC Community Grant program, individuals are offered evaluation and training in the following areas: Independent Living, Communication, Orientation & Mobility, Vocational Placement and Employment Assistance and Case Work.

About twenty-five people, aged 15-92, receive services at any given time. Each individual must have either a vocational goal or

choose to be a homemaker. Children of transition age can receive training through the Community Grant in areas that usually are not covered in the regular classroom curriculum. Learning how to prepare breakfast, make a sandwich or operate the washing machine may be typical goals identified. Room maintenance is another skill lacking in most teenagers; however, it is usually not a chosen goal! The mobility instructor may assist in finding a safe route to the local convenience store. The educational team may use the HKNC training team as a resource for developing vocational goals.



Instructor, Margaret Molloy and student Ramona Buxton-Anderson participate in the Grant program

The consumer and HKNC Grant instructor, with input from the state counselor, meet and develop a plan for services. The individual must be satisfied that the achieved goal has in some way improved his or her quality of life. HKNC receives funding only when outcomes of specific

goals can be demonstrated.

Mary is forty-five years old, married and the mother of two teenage girls. She has Usher syndrome II, a moderate hearing loss and can hear spoken speech in a quiet room only when using hearing aids. Mary's peripheral vision is also affected. She worked as a sales person 15 years ago but left job to raise her family. Mary has always been in charge, completing most of the daily household chores and, until a recent significant decrease in vision occurred, she had completed them with ease.

Mary contacted her state counselor and discussed the need to learn specialized techniques for cooking and cleaning. She asked if there was any technology for seeing the computer screen. She said she would have to get a job, but because she was afraid to travel alone and had limited vision, a job outside of the home seemed to be an "impossible dream." She wanted to learn safe techniques which would allow her to leave the house. It became clear: Mary wanted a job!

It was possible to offer Mary the training

she needed at home. It was important for her to maintain her role as a wife and mother, while working on her own personal goals.

With the HKNC Grant team, Mary completed several situational assessments; working for short periods of time at a flower shop, bakery and a factory. She explored her natural strengths and preferences, and enjoyed assisting a baker and waiting on customers. After a long search, she found a job in a bakery. Now, Mary had a reason to take part in O&M training - to get to work! She has been working for over a year now, and is using public transportation independently.

Providing services in an individual's home and community over a period of time has given HKNC staff insight into some of the factors affecting a person after leaving the Center. How does the family feel about allowing their family member who is deaf-blind to take on added responsibility? How does the physical layout of the home, work setting, or community affect the person's ability to use his newfound abilities? Can the person transfer the skills

demonstrated in a training environment to his new life situation? In addition, the Grant staff offer transition and follow-up training to students who have completed the comprehensive program at HKNC, returned home and are in need of specific support services at home or work.

The strength of partnerships can be measured by the benefit gained by each partner. Mary and other consumers talk about how their quality of life has been improved by having the instructors work within their homes and places of employment. The Grant staff feel these experiences have enhanced their personal and professional lives, as well!

INTERNATIONAL ESSAY CONTEST

The World Blind Union (WBU) in cooperation with the Canadian National Institute for the Blind (CNIB) invites any individual to enter an essay contest on the topic, "What Braille Means To Me." Essays should be

written from a personal perspective and describe how braille has affected or changed a life. Ten winners will be chosen. Each winner will receive \$500.00 (Canadian) and the winner's essay will be published in English, French and Spanish and distributed internationally. Published essays will become the property of WBU. Winners will be notified by mail. The decision of the judges will be final. Submissions must be postmarked or received electronically by February 1, 2000.

ENTRY RULES

The contest is open to writers who are blind, visually impaired, deaf-blind or sighted. There are no citizenship restrictions. Entries can be submitted in English, French, or Spanish. There is no entry fee. Entries may be written in print or braille; electronic submissions are preferred. The essay should be 1,000 to 1,500 words in length.

Each entry must include, on a separate sheet of paper, the writer's name, address and phone number. Essays should not include personal

identification within the text. Winning essays will be selected based on their ability to capture the judges' interest, and how compelling, powerful and creative they are. Entries will be judged by an international panel. Essays submitted will not be returned.

Entries should be sent to: AATB James W. Sanders, Canadian National Institute for the Blind, 1929 Bayview Avenue, Toronto, Ontario M4G 3E8, CANADA. E-mail: sanderj@east.cnib.ca.

THE MIRACLE - HELEN KELLER.

By Diane Schuur with David Jackson,

Reprinted from TIME 100

EDITOR'S NOTE: Much material has been written about Helen Keller and her accomplishments. For many people, she has become a role model of what can be achieved by a severely disabled individual if given the opportunity for full use of ambition and innate talents. Today, many deaf-blind men and

women are demonstrating that they can accomplish remarkable feats in overcoming the severe limitations caused by the loss of sight and hearing, using determination and ingenuity to attain their goals and greater independence. In the following article, we are given a brief and clear and poignant view of Helen's personal contributions to society at the beginning of the century when modern progress was just beginning to accelerate in every area of human endeavor.



Helen Keller was less than two years old when she came down with a fever. It struck dramatically and left her unconscious. The fever disappeared just as suddenly. But she was blinded and, very soon after, deaf. As she grew up, she managed to learn to do tiny errands, but she also realized that she was missing something. "Sometimes," she later wrote, "I stood between two persons who were conversing and touched their lips. I could not understand, and was vexed. I moved my lips and gesticulated frantically without result. This made me so angry at times that I kicked and screamed until I was exhausted." She was a wild child.

I can understand her rage. I was born two months premature and was placed in an incubator. The practice at the time was to pump a large amount of oxygen into the incubator, something doctors have since learned to be extremely cautious about. But as a result, I lost my sight. I was sent to a state school for the blind, but I flunked first grade because Braille just didn't make any sense to me. Words were

a weird concept. I remember being hit and slapped. And you act all that in. All rage is anger that is acted in, bottled in for so long that it just pops out.

Helen had it harder. She was both blind and deaf. But, oh, the transformation that came over her when she discovered that words were related to things! It's like the lyrics of that song: "On a clear day, rise and look around you, and you'll see who you are."

I can say the word see. I can speak the language of the sighted. That's part of the first great achievement of Helen Keller. She proved how language could liberate the blind and the deaf. She wrote, "Literature is my utopia. Here I am not disenfranchised." But how she struggled to master language.

In her book, "Midstream," she wrote about how she was frustrated by the alphabet, by the language of the deaf, even with the speed with which her teacher spelled things out for her on her palm. She was impatient and hungry for words, and her teacher's scribbling on her hand would never be as fast, she thought, as the

people who could read the words with their eyes.

I remember how books got me going after I finally grasped Braille. Being in that school was like being in an orphanage. But words - and in my case, music - changed that isolation. With language, Keller, who could not hear and could not see, proved she could communicate in the world of sight and sound - and was able to speak to it and live in it. I am a beneficiary of her work. Because of her example, the world has given way a little. In my case I was able to go from the state school for the blind to regular public school from the age of 11 until my senior year in high school. And then I decided on my own to go back into the school for the blind. Now I sing jazz.

As miraculous as learning language may seem, that achievement of Keller's belongs to the 19th century. It was also a co-production with her patient and persevering teacher, Anne Sullivan. Helen Keller's greater achievement came after Sullivan, her company and protector, died in 1936. Keller would live 32 more years

and in that time would prove that the disabled can be independent.

I hate the word handicapped. Keller would too. We are people with inconveniences. We're not charity cases. She was once asked how disabled veterans of World War II should be treated and said that they do "not want to be treated as heroes. They want to be treated as human beings."

Those people whose only experience of her is "The Miracle Worker" will be surprised to discover her many dimensions. "My work for the blind," she wrote, "has never occupied a center in my personality. My sympathies are with all who struggle for justice." She was a tireless activist for racial and sexual equality. She once said, "I think God made woman foolish so that she might be a suitable companion to man."

She had such left-leaning opinions that the FBI under J. Edgar Hoover kept a file on her. And who were her choices for the most important people of the century? Thomas Edison, Charlie Chaplin and Lenin.

Furthermore, she did not think appearing on the vaudeville circuit, showing off her skills, was beneath her, even as her friends were shocked that she would venture onto the vulgar stage.

She was complex. Her main message was and is, "We're like everybody else. We're here to be able to live a life as full as any sighted person's. And it's O.K. to be ourselves." That means we have the freedom to be as extraordinary as the sighted.

Keller loved an audience and wrote that she adored "the warm tide of human life pulsing round and round me." That's why the stage appealed to her, why she learned to speak and to deliver speeches. And to feel the vibrations of music, of the radio, of the movement of lips. You must understand that even more than sighted people, we need to be touched. When you look at a person, eye to eye, I imagine it's like touching them. We don't have that convenience. But when I perform, I get that experience from a crowd. Helen Keller must have as well. She was our first star. And I am very grateful to her.

CHRONOLOGY - HELEN KELLER

BORN June 27, 1880, in Tuscumbia, Ala.

1882. At 19 months old, has a high fever and becomes deaf and blind.

1887. Anne Sullivan becomes Keller's tutor.

1903. *The Story of My Life* is published.

1919. Begins four-year stretch appearing with Sullivan in vaudeville shows.

1936. Sullivan dies.

1959. *The Miracle Worker* airs on television. It is later adapted for the stage and film.

DIED June 1, 1968, in Westport, Conn.

THOUGH BLIND AND DEAF, CRUMPLER FINDS WAYS TO COMMUNICATE

By Dee Jenkins

**Reprinted from THE SAMPSON
INDEPENDENT, North Carolina**

Just the thought of someone interested in looking at his woodwork lights up William

Stacy Crumpler, Jr.'s face like a child in a candy store. During a recent interview with Crumpler he couldn't keep his hands still - his only means of communication with people due to his deafness - because he was so excited and wanted to show off all his beautiful woodworks, tools and pieces of wood.

Crumpler lives with his younger sister, Sabra Crumpler, on the original homestead just outside of Salemburg, North Carolina. Born deaf, diagnosed with Usher syndrome, he has always loved working with wood, following in his father and grandfather's footsteps. Crumpler and his sister are 2 of the 5 children born to the late William and Laurie Crumpler.

"He'll find a way to communicate with anyone that is interested in talking with him, especially about his woodworks," stated Ms. Crumpler.

Through special deaf-blind interpreter, Sherrie Cantrell from Wilmington, NC, Crumpler said he could make anything out of wood anyone wanted if they gave him a picture or measurements. Among some of his beautiful

work was a free standing swing for two, several bird apartments and porch railings.

Ms. Crumpler explained, "Stacy built all three of these buildings and he put the electric and plumbing in them by himself." She continued, "He just finished building the big dog pen and put insulation in the dog houses and the electricity to these lights," as she pointed to three very large flood lights hanging on the side of the dog pen.

According to Pamela Horne, deaf-blind specialist from the North Carolina Services for the Blind Department of Health and Human Services, Usher syndrome is an inherited condition which results in deafness and progressive vision loss due to retinitis pigmentosa. She went on to explain Crumpler's condition was named after the British ophthalmologist, C.H. Usher, who wrote a paper in 1914 describing several cases in which the link between congenital deafness and retinitis pigmentosa was stressed.

Ms. Horne explained Usher syndrome is transmitted genetically by an autosomal

recessive gene which both parents carry. Autosomal means the gene is not sex linked and both the male and female are equally affected by the condition. Retinitis pigmentosa is the degeneration of the retina which causes it to lose its ability to transmit pictures to the brain. It begins with night blindness and difficulty in adapting to bright light or rapidly changing light conditions and usually results in tunnel vision.

She said deaf people have a very hard time dealing with the loss of their eye sight because they are so dependent on their sight to communicate with people. It really makes it hard for them to read lips or sign language.

Crumpler is the fourth child of five. One older sister, Libby, is also affected with Usher syndrome. Another sister, Miriam, had Rocky Mountain spotted fever as a child. Both live in Kinston, NC. But Ms. Crumpler and sister, Pat Mitchell of Roseboro, NC, have no medical history of Usher syndrome.

Crumpler tells how he and his father worked on the farm picking peppers and selling them in order to purchase some of the first

woodworking tools he ever had after he graduated from the North Carolina School for the Deaf in Morganton, as he proudly showed off some of the tools his grandfather and father passed down to him. He still uses many of these same tools to do his own woodworking. He showed a very large tall porch column that his father had made, which he said he still cherishes because his father made it. He stated that he also cherishes the old tools he inherited from his father and grandfather.

He said he went to school when he was five years old and graduated with a high school degree in 1957. After graduation he returned to the farm to help his parents and to learn more about woodworking from his father.

"He would stay out here all night if I would let him," stated Ms. Crumpler. She said some nights she has to go into one of the shops and show him, by making him feel her watch, that it is past 10:00 p.m. and time for him to go in the house for the night. She said if he is in the middle of making something, he will continue to work on it until it is complete and it must be

perfect or he'll start over.

Ms. Crumpler said Stacy has made a lot of the furniture in their home as well as kitchen and bathroom cabinets for friends and neighbors. He has made coffee tables, end tables and even made her a stereo cabinet. Crumpler showed a screen window and storm window that he had made. Ms. Crumpler stated he could fix most anything that is broken.

He also is proud of five very large rocks which he said fell from the sky when he was a little boy. He said the rocks came down like a shower of rain and left big holes in the ground where they fell. "I ran away, I was scared when the rock shower started," Crumpler stated.

The rocks had several large holes in them where they could have been on fire or very hot from falling from the sky as a meteor. Jamie Perkins, rehabilitation counselor of the N.C. Department of Health and Human Service Division of Services for the Blind, confirmed the rocks were thought to have been from a meteor shower. She said she was told they had sent one or two of the rocks off to be tested and

from her knowledge of geology they look like rocks formed from a meteor.

Ms. Crumpler said, "Don't move one thing in any of these shops or he will know it has been moved," waving her hand around at the over crowded piles of wood and tools hanging on the walls. She went on to say that although Crumpler had never been able to hear, he could still see until recently when he started losing his vision. She said "he used to drive anywhere he wanted to go and do whatever he wanted until the past few years when his vision has gotten so bad." Crumpler and his sister have their own made-up version of sign language along with the regular sign language. She said if he comes in the house and tells her he needs a special piece of wood, she drops what she is doing and they go get whatever it is he needs.

"He's never been treated like a handicapped person. In fact I was in school before I even realized that not everyone knew sign language, because I grew up with it so I could talk to Stacy and Libby," said Ms. Crumpler. Ms. Horne said she enjoys every visit she has with

Crumpler because she says she always learns a new word or a new way to make people understand sign language from him.

Crumpler said if anyone needs some wood working done he would be glad to do it for them. He said he is looking for work because a lot of the people he used to do work for are gone. He said, "Just remember a cheap piece of wood makes furniture trash."

HERE AND THERE

Associated Services for the Blind of Philadelphia, PA, has a division that produces publications including cookbooks, crossword puzzles, biographies, and health issues. For information regarding cost and available titles of braille books, contact Delores Ferrar-Godzidba, Associated Services for the Blind, 919 Walnut Street, Philadelphia, PA 19107; or call (215) 627-0600, Ext. 214.

* * * * *

Horizons for the Blind offers a free catalogue of books and cookbooks for the visually impaired. For more information contact Horizons for the Blind, Inc., 16A Meadowdale Center, Carpentersville, IL 60110; or call (847) 836-1400.

* * * * *

Based in Columbus, Ohio, American Electric Power now provides its blind and visually impaired customers with their energy bills in braille. American Electric Power serves the following states: Ohio, Indiana, Michigan, West Virginia, Virginia, Tennessee and Kentucky.

* * * * *

U.S. West now makes telephone bills available to its customers in braille.

* * * * *

California Canes has introduced the Sidewalker cane as part of its line of carbon fiber canes. The Sidewalker cane is made of carbon fiber for strength and durability. It is two-thirds lighter in weight than comparable metal canes. The joints are computer ground and beveled on the inside so that folding it will not tear or cut the elastic. The elastic is a full millimeter thicker than previous California canes, and the finish is a reflective epoxy paint that is more durable than tape, giving it a high luster finish. Rigid canes are \$18.65 and folding canes are \$25.00. For more information, contact the company at (949) 489-1974.

* * * * *

The Carved Art Puzzle was specifically designed for visually impaired people by Kachina Internationale of Quebec, Canada. Its pieces are similar to regular puzzles except that they have raised pictures instead of photographs. Shapes available include a decorative candle,

eagle, tulip, butterfly, hummingbird, maple leaf, hot air balloon, lighthouse and the Statue of Liberty. For more information, contact Katchina Internationale, Inc., 285 Lauriel Street, Hull, Quebec J8X 3W9, Canada, or call (819) 775-9628.

* * * * *

The Color Macular Reader is a portable, handheld color closed-circuit television that offers variable magnification. It can be used for reading and writing, and sells for \$800.00. For more information, contact See Sea Development, 13144 Park Boulevard, Suite G, Seminole, FL 33776, or call (813) 398-0707.

GROWING BLIND IN SILENCE

By Mary Polly Easley

EDITOR'S NOTE: Mary Polly Easley has Usher syndrome I and lives and works in Seattle.

Growing blind, slowly, when one is already
deaf
is one of the hardest challenges for me, if not
the most
difficult of tasks,
especially when I feel disowned by my own
kin
as though having Usher syndrome is a grave
sin.

It was at the young age of eight
that I learned this ugly truth
from which I could only disassociate
and pretend this was all a lie...

Something to deny
lest my hopes and dreams, my aspirations
should die.

To avoid going 'insane' in silence,
I can only do my best to lead a life as a good
Jew
following my path of hope,
and occasionally stop to rest and bless my
mother
for going beyond the call of duty preparing

me for the
unexpected with her love,
her courage and her fearless heart, sometimes
pushing me
to the edge with quiet force,
when knowledge of Usher was scarce albeit,
a taboo.

At the age of 15 years, I learned from my
doctor
there's no cure, no one recipe for healing,
other than, for me, releasing
my sad and frightening feelings,
with tears, pain, rage, and many more tears
until my heart can grieve no more,
and I am able to learn new skills as the loss
of my sight
ceases to let me see the light
sparkling in your eyes - your soul, your very
core.
Each round of tears fills a certain flask which
I present
to my God with the questions we often ask-
"Why me?"

What can I do with myself? How do You
expect me to
make this a blessing in disguise?"

Fear of abandonment, of being mocked or
attacked,
of loss of independence and privacy,
Fear of the unknown and of uncertainty,
of past and present resentments;
fear that other dimension of spatial reality
and living in another time zone unknown to
me
which somehow moves in slow motion - but
with creativity
we all find ways to compensate.
Slowly I'm pulled into this other realm -
hesitant!
for I shall struggle and if I must, compete
with the more
competitive with a spirit never before heard
or seen.

All of these fears continue to haunt me by
day and night

as I focus on the lotus and my inner light,
my sense of vulnerability dissipates
strengthening me
as
I
grieve.

There is grief over one loss after another ad infinitum,
not so much that of sight, but rather the inevitability
of having to let go of stability and security;
to loose that capacity to drive, to bike long trips alone,
to feel safe when I'm alone,
to learn to use and trust a cane for mobility;
to teach another human being that life is full of choices
to reach out to others and teach the secret weapons
with which to fight for justice with peace...
Though I grieve, I shall overcome and find other ways
to transform my grief into positive energy - swimming the

butterfly, writing poetry, music, karate...

I wonder, will I proudly see my own
reflections of the
aging process
change in the mirror?

And will I observe how my very own
wrinkles form the
unique design?

When will be the last time I'll see
a newborn smile yes to life?

The ocean waves crashing and splashing in
patterns against
those mighty Northwest rocks?

When will be the last time I save another
creature or
person's life?

As I learn to cope and journey onwards on
my path of
hope,

I promise myself
I will never loose my smile
and I must always to life smile yes.

Each day I will count my blessings and in my heart

breathe a song:

Journey me toward You, my Healing God,
and lighten my burdens by walking with me
on my path of
hope;

protect me from the madness of Usher
and human injustice.

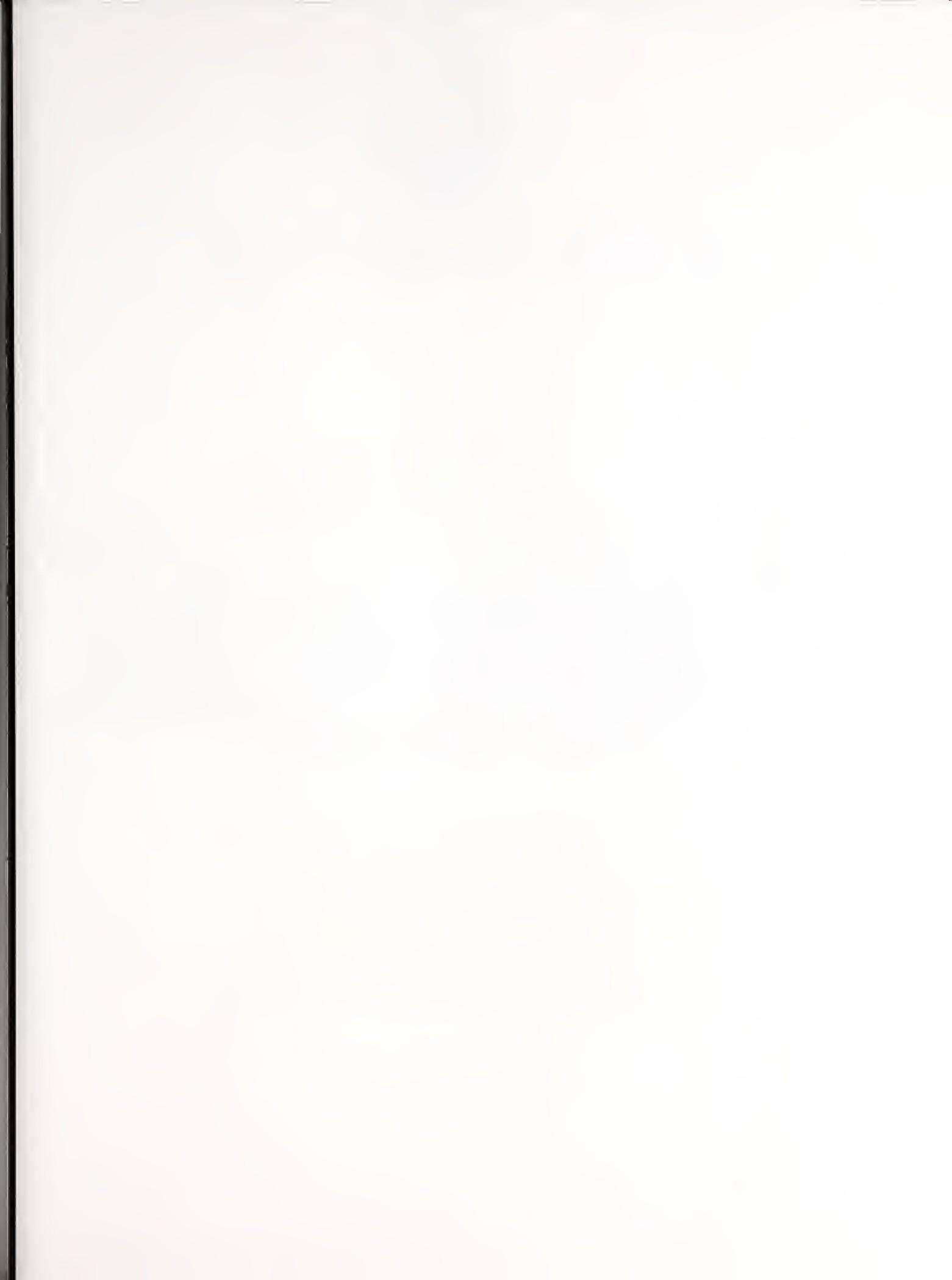
Please, just help me learn best how to cope
so I may plant seeds of hope.

Weeping in the nights, I bless myself by
blessing You
with knowledge, loving kindness, with care:
sacred words for every day as we walk my
path of hope

Every day for sacredness I invite You to sing
within my soul

Your favorite songs and Your echo bell tones
and I...and I will sing back to You,
through the touch of my fingers on the
keyboard, playing
out Your orchestra echoing within my soul.

I trust I shall be strengthened on this journey
as I grow blind in silence,
never giving-up on those who do not yet
understand,
with You at my side on this path of hope.



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EDITOR — ROBERT J. SMITHDAS, L.H.D., Litt. D., L.H.D.

Editorial Assistant — Allison Burrows

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EDITORIAL: THE NOTE TELLER

By Robert J. Smithdas, LHD, Litt.D, LHD

Several years ago, while reading a listing of new products for use by visually impaired and blind people, I was fascinated by the description of a small device called the Note Teller. I was intrigued by the device, which was described as a small, lightweight and very portable battery-powered money identifier capable of determining the value of United States paper money (bank notes), and announcing their denominations by synthetic voice.

I immediately realized that for the Note Teller to be useful for me and other deaf-blind users, it would need to be modified to produce coded vibratory signals that could be felt tactually. Remembering the vibrating Morse code signals I had used with an early telephone device for the deaf-blind, I felt sure it would require only a simple software change to make the device tactile.

Using the telephone number given in the article, I called Earl Bryenton, president of

Brytech Inc. in Canada, who had developed the Note Teller. From the beginning, Mr. Bryenton was attentive and interested. He agreed that the signals could be changed to produce vibrating signals that would be easy to recognize. Within a month, he sent me a prototype model to test.

For two weeks after receiving the prototype model, I used it constantly, enthralled at being able to identify and separate money into its various denominations without having to ask sighted friends for their assistance.

The Note Teller is easy to use. It has a three-level volume control on its front end, and a stereo plug-in jack for personal listening if one has some residual hearing. First, you place the Note Teller on a flat surface with the slot and guide on top. Then you insert a bank note lengthwise between the edge guides, making sure that the corners of the note are flat, and slide the note into the slot at the thick end of the device. When the bank note has been inserted far enough, the Note Teller turns itself on, identifies the value of the note with a specific signal, and turns itself off.

The original Note Teller, using audible signals to announce denominations of bank notes, is still available. The model using vibratory signals is now called the Enhanced Note Teller. The current price of the Enhanced Note Teller is \$395.00 plus shipping and handling.

Is the Enhanced Note Teller worth its price? I have owned one for eight years and I have never had to send it back for repairs. The 9-volt Duracell battery lasts for more than a year. When purchased, there is a thirty day money back guarantee if one isn't satisfied with the device. It comes with easily understood instructions in both print and braille. The device also has a six-month component warranty. If it does not meet your needs, you can return it within a month in its original packing.

Several deaf-blind persons have written to me inquiring about the Note Teller. I hope that the above information will be helpful to other readers of NAT-CENT NEWS who may yearn for a little more independence in handling

currency.

For more information concerning the Note Teller or the Enhanced Note Teller, contact: Brytech, Inc., 600 Peter Mohand Street, Ottawa, Ontario, Canada K1G 5Z3. Telephone: (613) 731-5800; FAX: (613) 731-5812.

**HELEN KELLER NATIONAL CENTER
THANKS LEONA HELMSLEY FOR
DONATION**

(Reprinted from the Port Washington News,
Port Washington, NY, November 1999)

Staff and clients of the Helen Keller National Center (HKNC) recently personally thanked Leona Helmsley for providing funding for the Leona and Harry B. Helmsley Conference Center, a major addition to the Center's campus that will greatly enhance its ability to serve deaf-blind clients across the nation. Plans for the 5,000 square foot conference center, funded by a \$525,000 gift from the Leona and Harry B. Helmsley Foundation, Inc., were announced by

Joseph McNulty, director of HKNC, at a reception honoring Mrs. Helmsley that was attended by government officials, local dignitaries, clients and staff.

According to Mr. McNulty, the bulk of the gift will be used to build the conference center, which will feature video tele-conferencing and closed circuit television to help HKNC provide training for clients, staff and its affiliates, including 40 state and private agencies serving the deaf-blind. The remaining \$25,000 has been earmarked to expand HKNC's library, a national clearinghouse for information on deaf-blind children and adolescents.

"Anyone who visits the Helen Keller National Center comes away impressed by its work, the dedication of its staff and the courage of its clients," said Mrs. Helmsley. "I am honored to be a part of it."

"Mrs. Helmsley's generosity permits us to more effectively disseminate information to our National Training Team, on-site staff, clients and professionals around the country," said Mr. McNulty. "This gift helps us ensure that people

who are deaf-blind receive the skills, training and support necessary for them to live and work in the community of their choice. We are extremely grateful."

"Funding to maintain and expand HKNC's programs and services is critical to our future," said Laurence S. Wizel, chairman of Helen Keller's board of directors. "This wonderful gift will help us fulfill our mandate to train people around the country and reach deaf-blind clients who desperately need our services."

One of the highlights of the ceremony was the appearance of Ashley Benton, a student from Clinton, NC, who arrived at HKNC in May and returned home in mid-October. With the aid of an interpreter, Ms. Benton spoke about the impact HKNC has made on her life and the training she received in braille, independent living and mobility. Ms. Benton graduated from East Carolina University in December with a degree in Family and Community Services. While at HKNC, she did an internship for her college in case management.

Ms. Benton was followed by Bob Smithdas,

assistant director of HKNC, who is himself deaf-blind and was the subject of an award-winning "20/20" interview with Barbara Walters last year. Mr. Smithdas spoke about meeting Mrs. Helmsley on her tour of the facility last April, personally thanked her for her generosity, and spoke about the progress that the deaf-blind population has made over the years.

"Today, the deaf-blind population has made major strides in terms of job opportunities, education and communication," said Mr. Smithdas, who was the first deaf-blind person since Helen Keller to obtain a bachelor's degree and subsequently went on for a master's degree. "Deaf-blind people are an often forgotten minority, who are usually overlooked in favor of larger groups of disabled people. We are grateful to Mrs. Helmsley for remembering us."

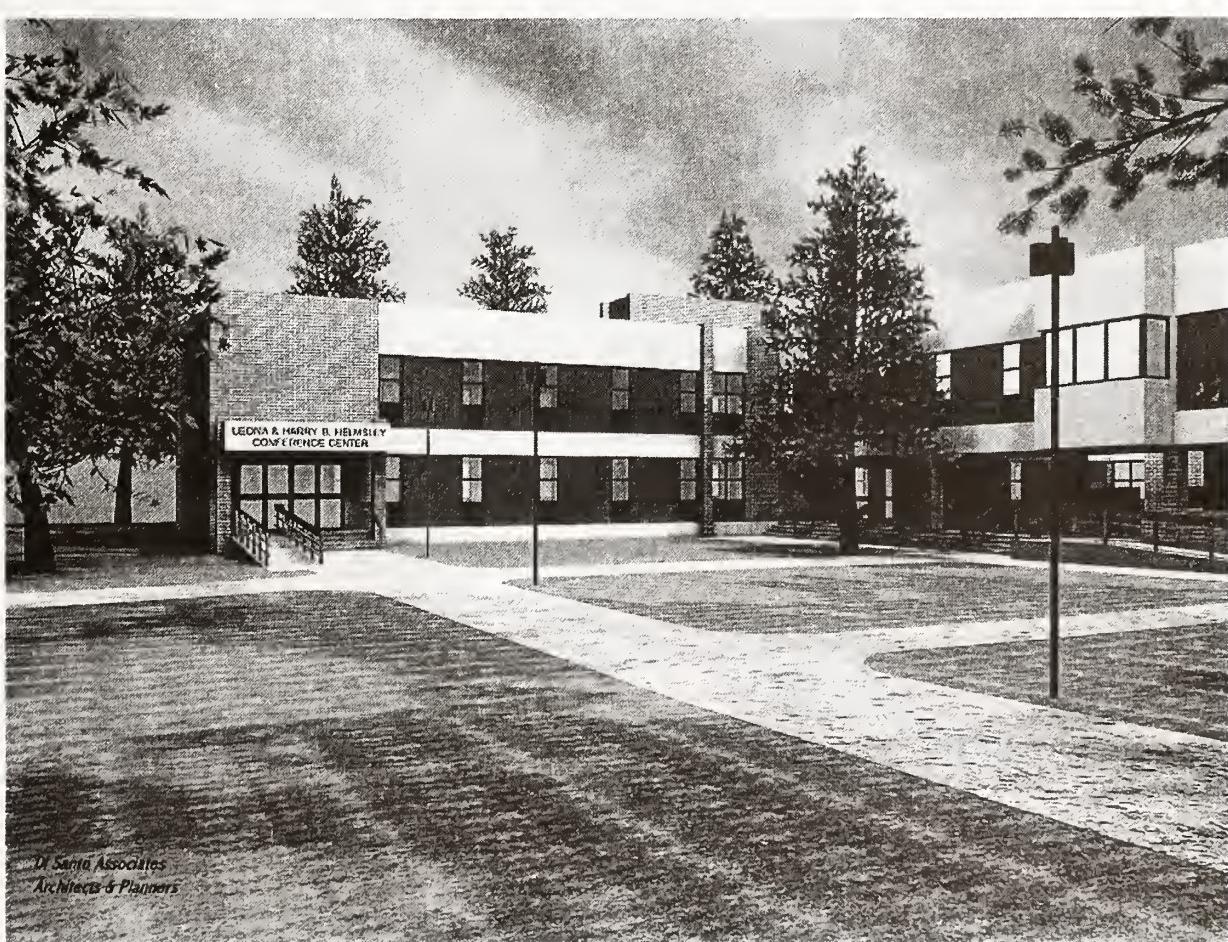
Mr. Smithdas then introduced Mrs. Helmsley who was presented with a gift by two HKNC clients: a vase made by Brian Farney and a floral arrangement by Ramona Buxton-Anderson, who obtained her current job at 1-800-FLOWERS through HKNC.

The current campus of HKNC was completed in 1976 and includes two buildings: a training facility that houses classes in independent living, assistive technology, vocational rehabilitation, communication and mobility; and a residence where clients live on-site for periods of time ranging from six months to two years, depending upon their level of need. The facility is open 24 hours a day, seven days a week.

Designed by architect Anthony DiSanto of Manhasset, NY based DiSanto Associates, the two-story Leona and Harry B. Helmsley Conference Center will house approximately 5,000 square feet of space with the possible addition of a 1,000 square-foot basement woodshop.

The Conference Center will also feature video teleconferencing and closed circuit television to facilitate meetings of HKNC's 150-member staff from 10 regional offices; town hall-style student meetings that often require as many as 20 to 25 interpreters; a variety of professional seminars; and an annual week-long

meeting of national affiliates. An existing conference room will be converted into a technology center. With the expansion of its library, HKNC can offer additional computers and technology to permit research and internships, as well as additional textbooks, journal subscriptions and articles.



FULL OF PURPOSE, AND FEELING THEIR WAY TO THE FINISH,

By Marcelle S. Fischler

**(Reprinted from The New York Times, NY
August, 1999)**

Anindya Bhattacharyya was eager and ready to go. Maybe a tad jittery - definitely full of potential excuses. Busy settling into a new apartment and job, he said, he hadn't had much time to train the past six months, just an occasional run around the track at the Helen Keller National Center in Sands Point, NY, holding onto the handrail.

Twice, he took a practice swim in nearby Hempstead Harbor. He worked out on the exercise bicycle in the gym once, but purchased a blue tandem bicycle only the day before his first triathlon - hadn't even gone for a ride!

"I know my first shock will be when I get in the cold water," he said, flipping his watch open and fingering the dial to see how many minutes were left until the 12th annual Seacrest-Tobay Triathlon would begin. "After that everything

will be fine."

Then Bhattacharyya, 29, who is known as Bapin, pulled off his T-shirt and pulled on a bathing cap to swim six-tenths of a mile in Oyster Bay Harbor, the first lap of the competition. But before wading in, Bhattacharyya, a computer technology specialist, had to be tethered to Jim Belanich, his support service provider.

Bhattacharyya is deaf-blind. He cannot speak. He communicates with tactile sign language, keeping his hand over his interpreter's, reading the movement of his knuckles and fingers.

"We are going to try to go fast," he signed to Belanich, figuring on completing the 15-kilometer cycling segment in 45 minutes and then running a 9-to 10-minute mile over the 5-kilometer (3.1-mile) course. "But the main goal is just to finish."

Triathlons can be difficult for anyone. But for Bhattacharyya and two other deaf-blind participants, Maricar Marquez and Brian Farney, swimming past the orange buoys,

pedaling the hills of Long Island's North Shore and running the back roads would be nearly impossible without a guiding hand and a system of signals and touches.

In the cycling segment, Bhattacharyya took the tandem bike's rear seat, tapping Belanich twice when he needed to stop. To slow down, he patted his side. When he needed water, he shook his hand. And throughout the run, Bhattacharyya kept his hand on top of Belanich's, which spelled out pebbles and potholes 20 feet in advance.

Even so, Bhattacharyya said the triathlon was just another adventure. He finished in 2 hours, 8 minutes, 670th out of the 900 individual participants.

Marquez, 27, came in 486th, in 1:45:38, well ahead of her 1:51:46 finish last year. She has Usher syndrome, a genetic disorder that has gradually robbed her of night and peripheral vision, leaving about a 10-degree field of tunnel vision. And Farney, 29, a computer student of Bhattacharyya's, who has been training for the past three months and also has Usher syndrome,

finished 503rd, in 1:58:09.

"I accept my deaf-blindness and then I can do just about anything," Bhattacharyya said. "I really don't feel I have limitations. I am not thinking that because I am deaf-blind, I can't do things. I can, so I accept those challenges, and I enjoy them."

He was stymied, he said, by having to walk up a hill during the cycling portion. And coming downhill, his bicycle chain came off. But that did not deter him from adding his results to the extensive curriculum vitae posted on his Web site. He manages it himself, using a special Braille display screen that hooks into the computer.

"Deaf-blind people are like everybody else; there is no difference," Marquez, a veteran rock climber, spelunker and sky diver, signed through her interpreter, Kelly Shanahorn. Marquez plans to run the New York City Marathon this year. "I like to do a lot of different things and get involved. I'm not the kind of person who stays home. I am fascinated by life."

Next spring, Bhattacharyya said, he plans to try snorkeling. And Farney said he was looking forward to a camping trip next weekend.



Former student, Brian Farney (L), works on the computer with Bapin while Dinah, Bapin's dog guide rests.

VOLUNTEER DOESN'T LET DISABILITIES GET IN THE WAY

(Reprinted from CENTERSCOPE, Swedish Hospital, Seattle, WA, October 1999)

If you think your morning commute is rough, consider the lengths that Janie Smith is willing to go through just to get to her volunteer job at Swedish Hospital in Seattle, WA.

Three days a week, she packs a collapsible white cane in a holster on her hip and pins on a button that says, "I am deaf and blind." Then she and her guide dog, Maggie, leave their home in Port Orchard and begin the long ferry and bus commute to First Hill.

Once there, she drops Maggie off at Volunteer Services, makes her way to Sterile Processing and, using her cane, follows a trail of abrasive tape that leads from the entrance of the department to her work station. And that's just the beginning of her day.

Smith, 48, has been volunteering in Sterile Processing since July. With the help of an interpreter and the staff, she has learned to

assemble various supply kits, reaching for items in carefully ordered bins and placing them in plastic bags. She consults an inventory written in braille when she needs to refresh her memory.

Unable to talk clearly or see or hear at all, Smith speaks by signing and listens by feeling the hand of a person signing to her. People who don't sign can use their fingers to trace letters in the palm of her hand, and she will do the same to them if her speech and hand gestures cannot be understood.

Jennifer White, a state-funded interpreter and vocational consultant, has been assisting Smith at the hospital, but once Smith is fully trained and familiar with her surroundings, she will be on her own. White says the staff has made it easier to train Smith and is impressed with the way they have accommodated Smith's needs. Smith is impressed - and touched - too.

"I was shocked at how willing and accepting the staff at Swedish have been from the minute I walked through the door," she says, using American Sign Language to express her

thoughts.

Smith has been deaf since birth, but became blind over the course of many years due to Usher syndrome. She finally lost all sight two years ago. Smith smiles often, but admits that being deaf and blind has frightened and depressed her at times. Working at Swedish provides a big boost. "I love it," she says. "It's the best job I ever had because the people here are so friendly."

A California native, Smith moved to the Seattle area 10 years ago with her husband, Dan, who is deaf. Together they raised six children. Her parents also moved to the area. In fact, her father, Frank McDermott, is a volunteer in the Pharmacy Department.

Although she may live in a dark and silent world, she is a bright spot to many people who work here. "I just think she's a remarkable woman and an inspiration to a lot of us," says Karen Stay, manager of Volunteer Services.

What sticks out in Stay's mind is something Smith said before becoming a volunteer here. "Nothing is going to get in my way," she told

Stay. "There are no barriers. I'll find a way to go where I want to go and do what I want to do."

EDITOR'S NOTE: Janie Bielle Smith was a student at the Helen Keller National Center in the mid-1980's.

TAKING THE REINS

By Marcelle S. Fischler

(Reprinted from The New York Times, Long Island Section, November 1999)

Tony So, 31, is deaf-blind. He Has Usher syndrome, a genetic disorder that first robbed him of his night and peripheral sight, leaving him with a five-degree field of tunnel vision. Not long ago, Mr. So checked into the Helen Keller National Center in Sands Point, NY, to learn to cope with his diminishing vision, acquire computer skills and be able to access information through Braille. For recreation, Mr. So, who is totally deaf, takes a karate-class and swims. He is also learning how to ride a

horse.

Out at the Pal-O-Mine Equestrian at Caumsett State Park in Lloyd Neck recently, Mr. So hoisted himself on to a chestnut quarterhorse named Yankee. Nervous at first, his legs shaking, he grinned broadly as he settled on to the bareback pad, caught his balance and sat up straight. Like most novices, he started with neither stirrup nor saddle, using his legs and thighs to feel the horse's power. "Squeeze the horse's belly with both legs at the same time," Lauren DeCosta, his independent living instructor, signed to him. Ms. DeCosta, of Oyster Bay, who works at both the Helen Keller National Center and Pal-O-Mine, has been riding since she was a teenager.

"This is something you can learn quickly," she said. "You may not become an Olympic rider that fast, but it is a skill you can gain competence in so quickly as opposed to other sports. It's immediate feedback. It's amazing in terms of the tactual sense. They are accomplishing something."

Accompanied by two sidewalkers, Mr. So

and Yankee moved forward circling around and around the ring. Eventually, his instructors told him he would be able to trot, then ride on his own. "I learned how to use the reins and stop the horse," Mr. So signed through his case manager, D'Andrea Weeks. "I was really excited and I was really motivated to go horseback riding. Yankee is a good horse. He does a good job. I've been petting the horses. I like the way this feels."

Horseback riding provides a sense of freedom for the visually and hearing impaired, said Lisa Gatti, director of Pal-O-Mine, a full-time therapeutic riding center for special needs children and adults on Long Island. It also builds confidence, self-esteem and a sense of independence.

"They are able to do something on a level playing field," Ms. Gatti said. "It carries over in the workplace and in the schools." Earlier, Mr. So learned to brush and groom the horse. Grooming helps build a sense of trust and familiarity with the horse, Ms. Gatti said.

"It was tough, but it was good," Mr. So

signed animatedly after he had circled the ring several times and reluctantly dismounted. Could he help lead the horse around, walking this time? Would he eventually be able to ride independently? Would it always be the same horse? And what if he fell off? The instructors reassured him.

"I'll pick it up as it goes," Mr. So signed. "I do want to ride again."



**Tony So, with his communications instructor,
Karen Neiman, visit a local bank as part of
Tony's training program.**

CENTER OPENS DOORS FOR DEAF-BLIND

By Betty Fuller

**(Reprinted from The Dispatch, Moline, IL,
September 1999)**

Imagine being legally blind and profoundly deaf. One such woman describes the experience. "If you poke a pinhole in a piece of paper and look through it with one eye shut, you can get an idea of what I can see. Now tape it to your head and sit in your office with the door shut. Don't talk to anyone and don't answer the telephone all day!"

Deaf-blind is a functional loss of both hearing and vision which impacts a person's ability to live an independent and productive life. It is not necessarily total deafness and blindness, but varying degrees of impairment.

No one's alone - fortunately there are agencies devoted to supporting and helping those who are deaf-blind cope with their disabilities and lead a happy and satisfying life. Such people can be found at the North Central Region

office of the Helen Keller National Center in East Moline, IL. The office is headed by Laura Thomas, regional representative. Clients must have both vision and hearing impairments. The Center helps clients from the age of 14 and up. Younger clients are given information and referral services to other agencies.

It would be hard to match Laura Thomas' enthusiasm and energy for her work. Her responsibilities include teaching, giving workshops, brain-storming and meeting with other professionals, assessing needs and services, and advocacy. She is also the mother of an 8-year old daughter. As a regional representative she spends a lot of time traveling. The region covers six states - Illinois, Indiana, Minnesota, Ohio, Wisconsin and Michigan.

Born deaf, she is proficient in reading lips and using American Sign Language. Ms. Thomas has taught sign language classes for 25 years and, for a break, is taking this year off from teaching. She is chapter affiliation chair of the American Sign Language Teachers Association.

When asked if her deafness posed problems with meeting her busy schedule, she looked puzzled. "It's not a problem," she said with a smile. Problems arise, she explained, when a battery goes dead for an assistive device used by a deaf-blind person.

"There's no pity here. Why should there be?" Ms. Thomas said. "I have learned to cope and make the best of it. I love my work. I have a wonderful network of friends and we keep in touch." Assistive devices such as the typewriter/telecommunications (TTY/TDD) are used by the deaf for communication over the phone. Ms. Thomas is excited about a new communication tool - E-mail. "It is so easy and fast," she said. The TeleBraille is a TTY/TDD, a communication device with a braille display attached. Messages are typed and produced both in print and in braille.

The Helen Keller National Center (HKNC), located in Sands Point, NY, maintains a Web site with related Web links which provide valuable information and resources. The Web site address is www.helenkeller.org/national.

Ms. Thomas does not train deaf-blind persons herself but trains others who work with them. "My job is to cultivate the skills of those who work with deaf-blind persons. I provide links to other known resources." She meets every two months with team members of the Illinois Advisory Board for Services for Persons who are Deaf-Blind.

As a regional representative she consults with individuals and agencies with the aim of assisting in the provision, development and improvement of programs and services for those who are deaf-blind. She will assess individual and community needs and works to develop a plan of service. As a regional representative, she will: Visit with the individuals, family, and program staff; facilitate team meetings and make recommendations for changes in programs; and provide staff training and suggestions to meet the person's needs. She also consults with state vocation rehabilitation personnel and others regarding assessment and development of an individualized plan for services; assists with the application process to HKNC; and conducts

follow-along and advocacy support to those who have completed training.

Regional Representatives also secure new and up-dated information which is added to the National Registry for the Deaf-Blind. Because of confidentiality, names are not used but numbers and needs are listed. Maintaining a registry is important, Ms. Thomas explained, in determining funding and to plan programs according to numbers and impairments. Persons who are deaf-blind in need of training for independent living or vocational skills are referred to HKNC.

There are any number of means and devices used to communicate with people who are deaf-blind. Communication can be accomplished by simple means such as eye contact, facial expression, body movement, pointing, touching object symbols, co-active movements, sharing activities and voice.

Minimal language skills include gestures, objects, pictures and picture communication symbols, communication books/cards and basic sign language. Formalized language skills

include assistive devices, speech/lip reading, written notes, print-on-palm, sign language (visual or tactile), fingerspelling (visual or tactile.)

There are also assistive devices such as teletypewriter/telecommunication, TTY/TTD, braille writers and Telebraille-TTY/TTD for the blind. In explaining all the devices used for the deaf-blind, Ms. Thomas said with a smile, "Whatever works, we use."

As a rule persons who are accepted at HKNC for training in independent living and occupational skills are sponsored by state vocational rehabilitation agencies.

The vocational rehabilitation training program at HKNC provides evaluation and training in vocational skills, adaptive technology and computer skills, orientation and mobility, independent living, and speech-language skills. Skilled professionals provide a comprehensive program of training so clients can live and work in their own community.

Society imposes another difficulty on those with impairments. Instead of viewing the

individual as a whole person, many see only the impairment. They are blind themselves to the abilities and accomplishments of those with physical impairments.

Ms. Thomas said she is proud of those who have overcome their physical impairments; have come to accept the reality of their lives and gone on to rich, full lives.

She talks of success stories in which deaf-blind work in agencies managing programs, food service, electronic assemblers, clerical work, business analysts, computer operators, teaching. They marry, are active in the community, enjoy sports, and work at productive jobs. They ask not for pity but for acceptance of themselves as individuals who can contribute their skills and talents to the community.

If you know of someone who can use the services of the Helen Keller Regional Office and has a TTY, call (309) 755-0021 for Ms. Thomas or the main line at (309) 755-0018. If you do not have a TTY, call the AT&T relay service, 1-800-855-2881. Give the operator the

TTY number and he/she will stay on the line to relay the conversation.

The Helen Keller Center's North Central Regional E-mail address is: hknc5ljt@aol.com; the office is at 485 42nd Ave., Suite 4, East Moline, IL 61244.

**IMPAIRED BAYVIEW TENANT WANTS
TO BE "ADVOCATE" FOR OTHERS**
(Reprinted from the Canarsie Courier,
Canarsie, NY)

Ramona Buxton-Anderson and her husband have raised three wonderful children and she has been an active community leader in her Bayview, NY, housing tenant association for over 25 years. Warm, out-going, competent and serious, with a sharp sense of humor, Anderson happens to be deaf and vision impaired. She has Usher syndrome II, a genetic condition combining congenital deafness, or hard of hearing, and progressive blindness due

to retinitis pigmentosa.

"In first grade I noticed I couldn't hear that well and my eyes weren't focused," said Anderson. "My parents thought I was slightly retarded, and they had my hearing tested. But it wasn't until high school that I received hearing aids. I used to sit in front of the class because I had taught myself to read lips (basic survival skills) and nobody noticed my hearing loss. I got around socially. I didn't want to be labeled as 'different', but it was hard to keep up. During my high school years I attended the League of Hard of Hearing in New York City, for tutoring classes and to refine my lipreading skills. I received my first hearing aids at age 18, just as I was preparing to go to work."

In 1968-69, Anderson attended Collegiate Institute for secretarial training when she was 19 years old, and happily met and married Robert, her husband. She was employed for a year at Albert Einstein College of Medicine before becoming pregnant and giving birth to her first child, a daughter, Francell. She returned to work at the Brooklyn Psychiatric Center as a

typist in the Occupational Therapy Department for two years. "Then I became a full-time mom when my second and third children, William and Jonathan, were born," she said.

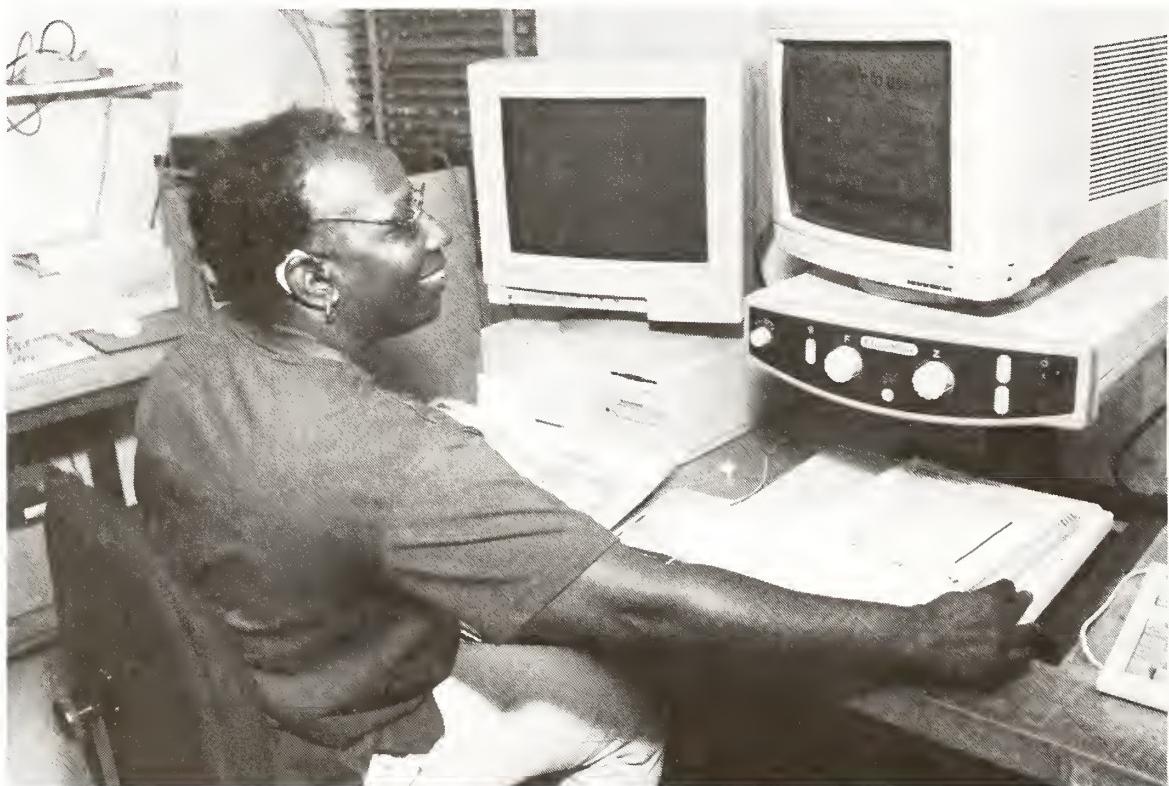
Always highly motivated, Anderson enrolled at FEGS (Federation Employment Guidance Services) to improve her typing skills, but her vision began to deteriorate. Though her night vision had been poor for many years, now her peripheral vision was rapidly declining. Undaunted, she switched careers and worked as a school lunch-room helper from 1980-1986. As her vision worsened, she was forced to stop working and undertook a new role as a volunteer in her Bayview housing area, eventually becoming first vice-president.

In 1994, after her first husband died, Ramona married Rossie Anderson. Trying to accommodate her deaf-blindness, and retain her independence, Anderson attended classes at the Helen Keller Services for the Blind in Brooklyn, to acquire special skills in mobility and receive some help from the audiologist.

Four years later she met a staff member

from the Helen Keller National Center (HKNC), which provides comprehensive vocational rehabilitation training and assistance with job and residential placements for people who are deaf-blind, headquartered in Sands Point.

Six months later she was a student in the HKNC residential program. After receiving training from the Mobility Department she was able to commute to New York City on Fridays and back to HKNC on Mondays using the Long Island Railroad.



Ramona uses a CCTV to review her typing skills lesson.

Anderson completed her HKNC studies in October, and stated her future goal: "I want to become an effective advocate for people who are deaf-blind. I want others to know about available services. This is a unique disability with special needs. Something as simple as sighted guide - don't grab my arm to help me across the street, I'll hold on to your arm. I want to help people. I like people. I just want the public to understand more about people who are deaf-blind."

COURAGE, DETERMINATION SHINE IN THE LIFE OF CLINTON NATIVE

By Lisa Carter, LIFESTYLE intern
(Reprinted from The Sampson Independent,
Clinton, North Carolina)

Industrious, bright, charming, self-possessed and, most assuredly, beautiful, Ashley Benton is one special person. With great dignity and humility she is an outstanding example for us all! To merely state that Ashley is a special

person is not enough; Ashley is an incredible winner.

Mrs. Benton was born deaf, and was raised in Clinton, NC. As a young child she attended Hargrove Elementary School through 6th grade, and then transferred to Eastern NC School for the Deaf in Wilson.

In a braille telephone conversation, interpreted by an operator, Mrs. Benton reflected on one of her Sampson County memories. She said, "I remember going to school when I was little. I remember all the teachers and I remember the principal. They were all a positive support for me."

Mrs. Benton continued to mention, "My family owns a produce farm in Sampson County. I will always have these memories."

After graduating from high school in 1994, she entered East Carolina University in Greenville, NC, where she recently graduated.

Mrs. Benton did not live on campus with the rest of her classmates, instead she lived off campus in an apartment. Her independence increased, especially when she chose to take the

college bus system to her classes every day. The difficulty of daily activities in life is what she is determined to defeat.

Her major field of study was family and community services, while her secondary focus was alcohol and drug studies, as well as psychology. Interpreters offer access to all of her classes.

Though Benton has worn hearing aids since she was two years old and is a proficient lip reader, at age 12 or 13 she began to realize that her night vision was declining and her peripheral vision was deteriorating. She and her family soon discovered that she had Usher syndrome I, a hereditary condition combining deafness, or hard of hearing, and retinitis pigmentosa, which can cause blindness.

Mrs. Benton commented on her reaction to Usher syndrome. "I was in a period of denial. The children at the deaf school used to make fun of me. Although, they were deaf they could still see and I couldn't. It was difficult and I was depressed. After the initial shock, I realized that I had to accept my condition so that

I could prepare for the future."

Considering that she was deaf and so were the other children, there was still a line that separated their impairments. "Deaf people rely on their visual sense so expressions and body language is imperative. When the other kids noticed that I did not have a strong visual sense, this separated us. I was segregated from the other deaf children by a different dorm and by activities that differed from them."

"But my parents, my sister and brother, my whole family have always encouraged me to do my best, to use my speech, to study diligently. That also includes my grandparents, my cousins....I have a big family! No one ever treated me in a different way." Ashley credits her family and friends for all of their patience and positive reinforcement.

When Mrs. Benton was asked how she continues to overcome her obstacles she said, "I have never been pitied or put aside. People have faith in me and they are always so positive. I want to make everyone proud of me." Mrs. Benton is a strong-willed person

absolutely determined to lead a normal life. One way she proved this was by marrying the special man in her life.

She recalled, "Last year, in December 1998, I married Ken. I went to school with my husband's brother in high school. His (Ken's) brother was also deaf. My husband is a sign language interpreter, so that's how we met. We dated and then married."

"It was at this point when I realized that I had to prepare for my future; for a family and a job. I had lived independently since graduating high school, but now I needed to learn braille, mobility skills, new ways to access the computer and retain my independent living skills by learning adaptive techniques."

When Mrs. Benton was asked about how she communicated with her husband and family she commented, "I use my voice and sign. With my husband I use my voice because he and my family encourage me to do so. With my friends, I usually sign."

In May 1999, Benton entered the Helen Keller National Center (HKNC) in Sands Point,

NY, for an eight-week evaluation and then a period of vocational rehabilitation training.



Ashley Benton (Center) enjoys a spring party with students Wendy Feliz (L) and Michaela Gibson (R).

While attending this unique comprehensive program, Mrs. Benton simultaneously completed a 15-week internship at another facility to fulfill requirements to ensure her college graduation in

December, 1999.

Mrs. Benton and her husband lived in an apartment which HKNC rents in the local community. It is one of three apartments available to HKNC students to help them prepare for their future independent living arrangements.

Mrs. Benton admits that she was learning but she was quick to add, "I missed my family and friends, but I learned so much at HKNC. I was never aware of possible services in my own community, or perhaps none existed, while I was growing up."

"My goal is to complete my education and training, and pursue a job in counseling and advocacy for people who are deaf and deaf-blind; to work with children, adults and families."

"If I had one message to send to other youngsters with disabilities, everywhere, it is this: go to school; acquire the best education; use every service available to you; work hard and you will succeed!"

THE HUMAN CONTACT EXPERIENCE

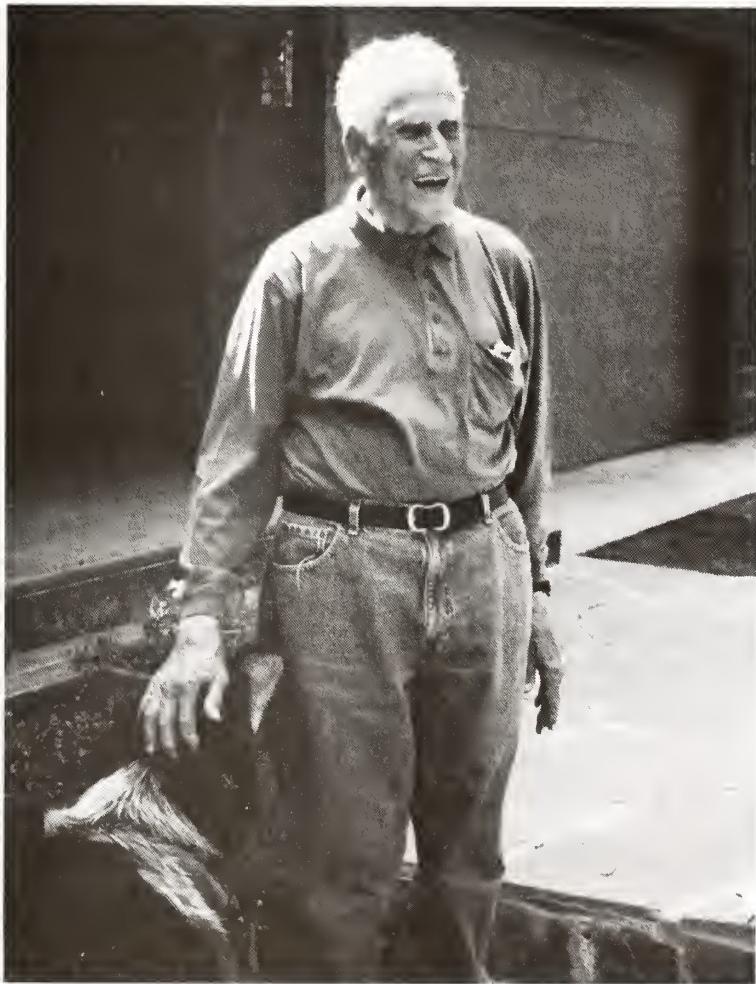
"THE MIDAS TOUCH"

by Bert Riedel, March 1999

In January of last year, I had the great pleasure of participating, with my son and daughter-in-law, in a workshop for the blind and deaf sponsored by Front Range Community College. This wonderful event was managed by Barbara Coffin, a knowledgeable and dedicated teacher in this important field. Toward the end of the workshop, Barbara asked me to speak to the group about my experiences with the problems of Usher syndrome. And, as an 87 year old with lots of experience, any suggestions or recommendations I might have. I was most interested in sharing my thoughts.

At my advanced age and pretty much at the terminal stage of Usher syndrome, meaning a total absence of sight and sound, I had some ideas that I wanted to share. After spending a fair amount of time contemplating the issue prior to the workshop, I suggested that there is as much a responsibility as well as a

requirement on the part of the sighted and hearing as there is on the Usher syndrome victim, to create a communication channel. And there are three principles that strike me as very important to assuring effective communications.



Bert Reidel

These principles appear very simple. However, people who are sighted and can hear,

often need to be reminded of the importance of each because they are pretty much taken for granted. Paying close attention to each, in my experience, not only makes communicating possible but even fun.

Principle No. 1 is this: Make certain that the blind person knows the identity of the person they are communicating with. It sounds so simple and it is. But it is not unusual for me to think I am talking to someone other than the person I am actually talking with. This is especially true when there are many people around. Imagine the confusion and the embarrassment that results. It is so important for the sighted-hearing to be aware of this.

Principle No. 2 is this: Provide the blind deaf person with a perspective on their surroundings. This is especially important when there are more than two people communicating. For instance, if I am at a table with five other people I really need to know who is sitting where, and any other information that will provide me a mental picture of my immediate environment.

Without that information deaf-blind people are pretty much lost and without a rudder to guide them. But when we have that information, our world is expanded and so is our ability to be a relevant participant in the joy of conversation.

Principle No. 3 is this: Once the first two principles have been satisfied, it is important for the sighted person to maintain physical contact with the deaf-blind person. It is just essential for us who can't see or hear to know that someone is still listening to us. A simple touch on the hand or on the shoulder every little while is a way of letting us know that you are listening and that we are participating in the "game of life".

Without regular physical contact, it is pretty normal for us to feel isolated and very uncomfortable. I don't like to keep asking someone if they are still there but after a minute or so without a physical contact, I start to wonder. It just makes everything go so much smoother if the sighted person keeps this in mind and provides frequent touch.

To me, these three principles make up the "Midas Touch". They may seem incredibly simple to someone who can see and hear but to those of us who can't they are a golden treasure opening up rich and wonderful channels of communication.

In September 1998, I suffered a fall on my stairs and ended up with a broken neck. After a short stay in the intensive care unit at Swedish Hospital in Denver, I spent several months recuperating at the Lifecare Center in Evergreen, Colorado. I made many good friends while I was there and I was amazed at how many times I experienced the Midas Touch from the many caring staff.

In particular I'll never forget the special connection I had with Marvin. He really knew the importance of identifying himself and keeping me connected with him through touch. He had a special touch and he made a point of reaching out to me. No matter where I was, in my room, in the dining room, at the piano, or in physical therapy his hand would reach out and I would identify it immediately. And I

would say, "Hi Marvin, how are Cindy and the kids." Boy, it made me feel so good and so normal.

At other times, Marvin would point to my beard because he had helped me to shave when I first met him. You see, I was wearing a metal contraption called a halo, which is the way they stabilize a broken neck, and had a heck of a time shaving in certain spots. Marvin always made me feel alive and happy. And he did it solely through touch. Of course, there were many, many nurses and assistant nurses and others who made me feel happy and part of the human race. They also did it by using the "Midas Touch."

I have many wonderful and new friends who have helped make life happy. I have received the "Midas Touch" many times and for that I am very grateful.

MY FRIEND - THE WIND

By Bert Riedel

At the end of my path, I often sit at my mountain bench
Accompanied by my friend - the wind.
He is a remarkable friend,
When one considers all that he has done.
Throughout the seasons, he has many moods;
Now a gusty wind, I grab my cap and grin.
Now tender and soft touching my face with a caress, which makes me smile.
Now a monumental blow that startles me to stand and resist and enfold myself for warmth.
And then self-effacing with a lovely, warm experience which reminds me of the beauty of spring in the rockies.
The wind is everywhere, all the time, and completely covers mother earth.
Consider the orchid, one of nature's lovely beauties,
Whose life-bearing seeds are blown to all corners of the earth;
In their earthly homes, with help from mother

nature, new life takes shape producing even more beauty.

In this way, my friend assures that all parts of the world share in abundance.

While the wind performs its incredible wonders for the benefit of such a large plant,

I am blessed that he takes the time to visit me and be my friend.

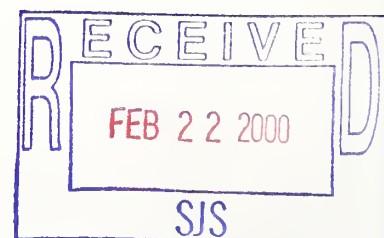
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EDITORIAL: THE IMPORTANCE OF BRAILLE FOR THE DEAF-BLIND

By Robert J. Smithdas, LHD, Litt.D, LHD

Ever since it was conceived and developed during the early years of the nineteenth century, braille, a tactual system for reading and writing raised texts, has been a boon to people who are visually impaired, blind, or deaf-blind.

Invented by Louis Braille, a young Frenchman who was blinded by an accident while playing with a sharp awl in his father's harness shop near Paris, braille has enormously expanded horizons of education for the visually disabled, improved their knowledge and literacy, and opened the gates of opportunity in an ever-growing choice of life experiences and professions.

What print offers sighted individuals, braille provides for those who are visually disabled. It unlocks vast sources of

information, enriches language and knowledge, provides a means of self-expression and communication, and unlocks the entertainment and wisdom buried in the pages of books and modern magazines.

For deaf-blind people, braille has an especially significant and meaningful influence on their lives today. Advances in technology and the development of special assistive devices are making it possible to access a wide variety of sources of information and increase awareness of what is happening in the world they cannot see and hear.

Telecommunication devices are making it possible for deaf-blind people to contact friends and family, order merchandise or services, or call for emergency assistance via the telephone. Computers and braille displays are opening up the great potential of the Internet. All of this has the effect of promoting a new sense of self-confidence and freedom.

We are proud of the fact that within the past few years, four of our instructors at the Helen Keller National Center have become certified as Braille Transcribers by the Library of Congress, National Library Service for the Blind and Physically Handicapped. With the help of Allison Burrows, another staff member, they have mastered the intricacies of braille and its rules and are now able to teach new students how to use this method that can open up a world that seemingly has imposed difficult barriers and restrictions to success and happiness.

YOU CAN MAKE A DIFFERENCE IN THE LIFE OF A PERSON WHO IS DEAF- BLIND

**By Barbara Hausman, Director, HKNC
Public Relations Department**

Share Helen Keller's vision by participating with agencies and organizations

worldwide in the Helen Keller National Center's (HKNC) 2000 AWARENESS CAMPAIGN whose theme is "YOU CAN MAKE A DIFFERENCE."

Since the early 1960's, people who are deaf-blind have benefitted from amazing technological advances. But they still need your help and personal support as an employer, co-worker, neighbor, classmate or friend in order to achieve full participation in American life.

Like other people with disabilities, individuals who are deaf-blind have become empowered by assistive and computer technology. High-tech adaptive equipment has enabled people with vision and hearing loss, or other severe impairments, to overcome some of the long-standing obstacles of isolation and communication. Improved models of equipment are continually being introduced. Keeping up with mainstream technology is a difficult task - and an extremely expensive

one.

Originally proclaimed by Congressional resolutions and Presidential signature 16 years ago, awareness activities and events featuring information about significant vision and hearing loss, or deaf-blindness, now occur throughout the year, beginning in June, the month of Helen Keller's birth date.

This millennium campaign features Winnie Tunison, a wife, mother, grandmother, recent cum laude graduate from Gallaudet University and inspirational role model for others.



Born deaf, Tunison began to lose her vision at age 31 and was completely blind nine years later. She has Usher syndrome I, a genetic condition combining deafness and gradual loss of vision due to retinitis pigmentosa. Depressed and filled with despair, Tunison entered the Helen Keller National Center for vocational rehabilitation training in 1992.

After acquiring a host of skills and building her self-image, she was motivated by the HKNC staff and her peers to study for her SAT exams (learning algebra from scratch) in preparing for college entry. Five and a half years later, she earned her BA, with distinction, in Communication Arts from Gallaudet University.

After graduation, she became an ambassador for the University as a motivational speaker, touring through nine European countries for two months. Winnie is now employed as a teacher/counselor and plans to have her own ceramics business one

day.

"People see an individual who is deaf-blind and they tend to pity them," said Tunison. "They don't know how to deal with folks who are deaf-blind. All they have to do is open their hearts and minds, learn to communicate and get involved."

"Americans with disabilities still face a sharp gap in securing jobs, education, transportation and many areas of daily life, including recreation and worship," says a 1998 landmark Louis Harris Survey commissioned by the National Organization on Disability (NOD). "At a time when the U.S. unemployment rate is at an historic low and there is a crying need for workers, it is astounding to learn that the employment gap between disabled and non-disabled workers remains so wide," said NOD President Alan A. Reich. "America must remove attitudinal and physical barriers in the workplace and all other areas of life."

What can Americans do to close these gaps? The survey suggests:

- 1. Employers can re-examine their practices and seek out and hire people who are deaf-blind or have other disabilities. It only costs, on average, \$300 to accommodate a worker.**
- 2. Community groups, service and religious organizations can adopt plans to include people with disabilities.**
- 3. Recreational, cultural and sports groups can ensure full accessibility and encourage participation of people who are deaf-blind or have other disabilities.**
- 4. Americans can recognize people with disabilities as positive contributors to their communities.**
- 5. Americans can extend a hand as a volunteer, support service provider or intervenor to a deaf-blind individual in their neighborhood, at the local gym, food market, church/synagogue, or local school system.**

6. Americans can encourage the media to continue to ensure that people with disabilities are portrayed fairly as individuals in public and private life.

All citizens, health organizations, civic groups, libraries, businesses, schools and agencies are encouraged to plan state and local activities during the month of June, and especially during the week of June 25 - July 1.

A sample proclamation, radio public service scripts, a list of activities, a poster, ad slicks, and this press release are available at no cost from the Public Relations Department, Helen Keller National Center, 111 Middle Neck Road, Sands Point, NY 11050, or by calling Barbara Hausman, 516-944-8900, ext. 325 (Voice), 516-944-8637 (TTY), 516-944-7302 (Fax), or E-mail: hkncpr@aol.com

HKNC NATIONAL REGISTRY
by Nancy O'Donnell, Coordinator of the
National Registry
Reprinted from HKNC UPDATE
Winter 2000

Have you ever wondered how many deaf-blind people there are in the United States? For many years, there has been no way to answer this question for the "over 21" population other than educated guesses.

Estimates have varied greatly. For example, in 1996, only 437 individuals were reported to be deaf-blind to the Rehabilitation Services Administration. On the other end of the spectrum, Schein & Delk determined that 356 people per 100,000 experience a combination of vision and hearing loss.

In an effort to gain a more accurate count and an understanding of the needs of this population, the federal government recently authorized HKNC to maintain a national

registry of those who are deaf-blind. We are very excited about this project!

Getting Started

Over the years, HKNC has collected information on the clients we have served through our programs at headquarters, in the field, through our affiliated agencies and from other agencies or interested individuals. This information, however, has not been available on a national basis. During the summer of 1999, we enthusiastically began the process of compiling this information into a national database.

Beginning with records stored in our archives, we entered data on thousands of individuals. These records include the cause of their deaf-blindness, severity of hearing and vision losses, methods of communication, residential situations, employment status and training needs. We are currently working with a programmer to combine this information

into one workable database.

When this database is operational, we will have a better understanding of the numbers of people with various syndromes that cause deaf-blindness, such as Usher, CHARGE and congenital rubella. We will be able to determine the most commonly reported methods of communication, the numbers of people using hearing aids or who have had cochlear implants, services that are available and services that are needed. All of this information will be accessible in national, state, and local profiles.

This type of demographic information is critical to agencies planning adult services for this population, to university programs preparing teachers to work with those who are deaf-blind, to agencies providing residential and employment services, and to the federal government as it develops initiatives and priorities for funding.

The registry will not replace the current

comprehensive system of collecting census information for children aged birth to 21, compiled by Teaching Research in cooperation with the State and Multi-State Deaf-Blind Projects. However, we will include anyone who is deaf-blind, of any age, on our registry.

If you would like to register yourself or obtain an application for someone you know, you can request a copy of the registry form from Nancy O'Donnell, HKNC, 111 Middle Neck Road, Sands Point, NY 11050. Copies are also available at our website: www.helenkeller.org/national under Special Projects - Registry.

JUST THE RIGHT JOB

**By Barbara Hausman, HKNC Director of
Public Relations**
Reprinted from HKNC UPDATE
Winter 2000



Cindy and her guide dog, Morgan, with co-worker, Karen at Walgreens.

After nine months, Cynthia Moss completed her vocational rehabilitation training at the Helen Keller National Center (HKNC) in November 1998, and is now living independently and working in Danbury, CT, as a service clerk at Walgreens. "Cindy" has Usher syndrome I, a genetic condition combining congenital deafness and progressive blindness due to retinitis pigmentosa.

Kathy Mezack, HKNC supervisor, vocational services, explained that, "Cindy

exemplifies the Center's 'person-centered' approach to training, because Cindy wanted a job which included her newly acquired computer skills and she didn't want to settle for a regular 'clerk' position. Accompanied by her vocational staff, Cindy canvassed the businesses on Main Street in Danbury, CT, (where Cindy had relocated), seeking employment. We felt that Cindy was well prepared and well trained for the job at Walgreens because it involved some work on the floor, as well as checking the computer each day for new prices, printing MYLARS (unit prices and descriptive labels), using search features to find locations of items and performing other basic data entry/retrieval tasks."

Originally hailing from Rochester, NY, Cindy attended the Rhode Island School for the Deaf and completed an Associates Degree Program in Machine Shop at RI Community College. She worked for six years engraving

trophies and plaques, and then briefly worked as a hostess for Homestyle Family Buffet. But when she entered HKNC she clearly wanted to explore clerical work.

Though she had no experience with computers, Cindy was introduced to, and soon acquired skills for, using Microsoft Word, America Online and Microsoft Excel in HKNC's Computer Technology Department. She honed her typing skills in class and during several work experiences at the Center and in the community. In her Work Adjustment Group, she and fellow students discussed pertinent issues such as legislation affecting people with disabilities in the workplace (i.e. ADA and social security system), job seeking skills (completing a resume, preparing for an interview), employee benefits, and problem-solving at work. She had a weekly work experience at the Nassau County Social Security office and demonstrated the ability to work as an assistant or data entry clerk.

"Cindy's a hard worker and highly motivated," said her case manager. "She was very involved at HKNC during her training; in Town Hall meetings, with the Usher support group, in recreational activities and definitely in her job search. Just recently, in addition to the magnification glasses she had always worn, Cindy purchased adaptive aids she now requires: two hand-held magnifiers and a screen enlargement program for her computer at work."

Cindy communicates with her Walgreen Supervisor Alfredo Porta and co-workers in several ways. She uses communication cards like "Good morning. What would you like me to do?", "Where is this item?" "I need help, please. Thank you.", or through note writing and demonstration. During her first week at work, Cindy learned many new tasks from HKNC's vocational staff. She received mobility training for the route she must take using public transportation, and for her

immediate work area. Porta said, "Sometimes it takes time to teach Cindy a new task, but we do just fine. You can set your clock by Cindy. She does everything right on the nose. She even taught us a few signs and often asks certain people, like our bookkeeper, for help. In fact, our bookkeeper says she would like to learn more American Sign Language! We are pleased to have her as part of our staff."

"Mostly I do stocking and price labeling at work," said Cindy. "I feel confident most of the time and I have a good sense of being. It keeps me busy. Everything is beautiful."

At this time, Cindy works over 25 hours per week, Monday through Friday, 9 a.m. to 2 p.m., which fits her schedule as a working mother. "This means a lot to Cindy," notes Mezack. "She is earning her own money. She's very independent in advocating for herself, very responsible, and an upbeat person. It's a successful story!"

A NEW LIFE - A NEW BEGINNING

By Celine Bush, former HKNC student

Reprinted from HKNC UPDATE

Winter 2000

It was springtime, a time of new life and new beginnings. But for me, it was a time of pervasive sadness and loss. The Easter season was rapidly approaching and I was faithfully practicing my flute. I would be playing for many church services this Easter season, but I knew that this year, 1997, would be the last time I would be playing flute with our church choir.

I have been blind from birth and music has been an integral part of my life. My earliest memories of music are those of my mother singing lullabies to me. At the school for the blind in Jacksonville, Illinois, I learned how to play the piano and clarinet and sang with our girls' glee club and mixed chorus. In college I sang with several choral groups, and since

then, with church choirs. Since 1985, I have played flute at church and for senior citizens, weddings and funerals. But now my world was falling apart. I could no longer hear well enough to play with piano or organ accompaniment. Chords and harmony sound grossly distorted, making melodies unrecognizable. Since a city bus hit me in 1966 and I sustained a skull fracture, my hearing has been deteriorating. And then, after a whip-lash injury in a car accident in the fall of 1995, my hearing took a sharp plunge.

In the spring of 1997, my life took a new and unexpected direction. Working with Laura Thomas, Helen Keller National Center (HKNC) regional representative, North Central Region, I prepared to enter HKNC as a student. After reading the brailled information Laura had given me, I realized that I could greatly benefit from their services. As a blind person I had traveled

independently, having experience with both a cane and a guide dog. But now, with my hearing severely impaired, I knew I needed specialized training. I knew, too, that I needed to learn tactal sign language, computer skills and seek help with my job search. Without a doubt, HKNC was the place for me.

I'll be back home in eight weeks, I told myself, my family and friends. Eleven months and three training periods later, I completed my studies at HKNC. The HKNC training was invaluable as I strove to cope with everyday life and sought employment. But for me, a totally unexpected gift in my year at HKNC was of friendship and healing. Through discussion groups with my peers, which are a part of the curriculum at HKNC, I had learned that I am not alone in my struggles. We shared our stories, our fears, our hopes for the future. Through laughter and tears we shared good times and bad,

striving to come to terms with loss and change in our lives. For me, this interaction with others was a time to begin the healing process, to work through the grief brought about by loss, and to reach a point of acceptance. Because I am a musician, it was inevitable that another art-form would emerge – that of creative writing. Although I have always enjoyed writing poetry, I had done very little writing through the years.

As a student at HKNC, I was again inspired to write. Looking back, the writing seems like a natural transition from music; it has given me new direction for my creativity. Although I can no longer play flute with accompaniment, I still play solo for special occasions. In August of 1998, I played flute at the wedding of my daughter Beth. And in January of 1999, I played at the funeral of my niece Michelle. One of the work experiences I had as a student at HKNC was to play flute for the residents of the Sands Point Nursing

Home.

Darcel Jackman, my vocational instructor, was the person who was responsible for connecting me with Horizons For The Blind, a not-for-profit organization in Crystal Lake, Illinois. The director and founder of Horizons, Camille Caffarelli, has been blind since birth. In September of 1999, I began a four-month apprenticeship there. Horizons produces materials in braille and large print and my job is proofreading braille documents and making note of the errors. When a computer and braille display become available I will be making corrections on the computer. I am looking forward to becoming a full-time employee at Horizons.

After so many years of struggle, my dream of becoming gainfully employed is coming true. This would not be possible without the dedication of so many people at HKNC and those who are with me now. One person who has been a very special link in my transition

from HKNC to a new community is Amy Parker, Community Placement Specialist for the North Central Region of HKNC. My transitioning wouldn't have been possible without the calm and gentle strength of Amy.

I don't know what the future holds; I only know that I am much better prepared than I was before my student days at the Helen Keller National Center.

SUCCESS STORY

By John Hanc

Excerpt reprinted from NEWSDAY, Long Island, NY

Last summer, Maricar Marquez and some friends went out to dinner at a Chinese restaurant. At the end of the dinner, she cracked open a fortune cookie. "The message was 'Everyone is rooting for you,'" she recalled. "And that started me thinking about different things I'd accomplished in my life

and what the next step was."

Marquez' accomplishments are staggering. Born in the Philippines with a debilitating inherited disease known as Usher syndrome, she is deaf and legally blind. But that hasn't stopped her.

At 28, she has earned both bachelor's and master's degrees and is a senior habilitation specialist at the Helen Keller National Center in Port Washington, NY. She is also an athlete. Marquez completed the Seacrest Tobay Triathlon, a swim-bike-run event, in 1998 and '99.

After that last triathlon in August, she was ready for a new challenge. "The cookie started me thinking," she said. "It doesn't matter that I'm deaf-blind, because I'm the same as everybody else and I can do what everybody else can do. And that's how I came up with New York."

The New York City Marathon, that is. For Marquez, running the 26.2 miles through the

crowded streets of the five boroughs required a specially trained guide. Her friend, Jim Belanich of Port Washington, served the role ably. But Marquez also had to deal with serious knee pain that cropped up the week before the marathon. "Two days before the race, I wasn't even able to run 2 miles," said Marquez, who speaks through sign language via an interpreter. "I was petrified that I'd never be able to finish the race."

But she and Belanich were at the starting line along with 31,000 others. Tethered together at the wrist with a strip of flexible fabric, they made their way over the Verrazano Bridge and through Brooklyn.

Then at the Pulaski Bridge, the race's half-way point, "all of a sudden I started to feel pain in my knee," Marquez said. "I got really upset at that point." She gritted her teeth and slowed her pace. Although far from the 5 1-2 hours she had hoped for, Marquez and Belanich crossed the finish line in Central

Park in 6 hours, 48 minutes, 32 seconds. "It was exhilarating, amazing, wonderful," she said.

The crowd roared its approval, and a number of friends were there to greet her. The fortune cookie was right.

SEIZING HER DAYS - JANIE'S STORY

By Cecelia Goodnow

Reprinted from the Seattle Post-Intelligencer

Being with Janie Smith is like looking through a one-way mirror. It's almost voyeuristic, openly studying her intelligent, expressive face, knowing that a discreet cough or shuffle of the feet won't give you away - knowing she doesn't realize you're just across the room. In her aqua scrubs, surgical cap and white oxfords, Smith looks like any other worker in Swedish Medical Center's Sterile-

Processing Department.

What sets her apart is her blue lapel pin, the size of a demitasse saucer. Its bold print announced, "I am deaf and blind."

Here, in the bland atmosphere of the workaday world, Janie Smith is taking back her life. "I don't want to stay at home all the time," says Smith, who donates her labor three days a week. "I'd just get bored." Besides, she adds, "I need to know how to take care of myself."

Her co-workers display quiet admiration for the woman battling darkness and silence in their midst. Some call her "our next Helen Keller." "You gotta meet this woman to realize she's not an ordinary person," says Smith's supervisor, Pennie Clemmer.

Smith, 48, has Usher syndrome, a rare genetic disorder that has robbed her of hearing and sight. There is no cure. Like others with the disorder, she was born profoundly deaf and slowly lost her vision in

adulthood due to retinitis pigmentosa, a degenerative disease of the retina.

At 19, Smith started to experience night-blindness, the first step in her inexorable visual decline. "It was like I was wearing sunglasses," she says, signing into an interpreter's hand. "I couldn't see very well." Later she developed tunnel vision and could only watch helplessly as her visual field narrowed like a door slowly swinging shut.

Two years ago her world went dark.

Smith, who lives across the Sound in Port Orchard, began volunteering at Swedish last July. In the hushed chambers of the Sterile-Processing Department she assembles kits of medical supplies. Her main job is to restock the bedside drawers used by intensive-care nurses. Clemmer has told her which supplies each drawer must have. There are 30 different items in all, including sterile gauze packs, alcohol preps, 4 types of syringes, lotion bottles and different types of

IV tubing. She also prepared postpartum packs of diapers, soap, comb, bulb syringe and other supplies for the nearly 400 babies born at the hospital each month. Last month she spent her spare time at home sewing and hand-decorating 100 infant bunting shaped like Christmas stockings to swaddle babies born at Swedish over the holidays.

Although she isn't paid, she works with the focused intensity of a new recruit bucking for promotion. Soon she hopes to turn her volunteer skills into a paying job at Swedish. Although the idea is still in the pipeline, her acting department manager, Thomas Fields, says he's enthusiastic about trying to make it work. It's an exciting prospect and a rare chance for someone with her disabilities. "Job opportunities for deaf-blind people are severely limited," says Jennifer White, Smith's interpreter and job coach. But, she added, "the limitations are only set by the environments deaf-blind people are put in."

White, who runs Able Opportunities Vocational Consulting, has spent a year grooming Smith to beat the formidable employment odds. The State Division of Vocational Rehabilitation is paying for White's services.

Smith is an easy person to like. Dark-haired and solidly built, she has the pleasant, open face of a good-natured farm wife who has weathered a few crops failures and come out smiling. She has made friends at Swedish but says some people are "a little bit scared because they've never met somebody who's deaf-blind." Even so, she says, "This is the best place to work. It's so cool." She recently told her colleagues so, in a hand-printed note of appreciation. Although her syntax is unusual, she has a strong grasp of English for someone with her disabilities.

"Hi, there," she wrote. "I want to say thank you so much for letting me to work in sterile supply lab room...I'm anxious can

communicate you all if you can learn to ASL (American Sign Language) or fingerspell!"

They're working on it. Smith and White have held several well-attended training sessions. Some hospital employees now wear finger-alphabet cheat sheets on chains around their neck so they can spell brief messages.

Clemmer has grown especially adept at signing into Smith's hand, allowing her to feel messages she can no longer see. Although they have formed a strong bond, they rely on after-hours e-mail to add the fine brush strokes of nuance and detail.

"Did you get what I was saying this afternoon?" Clemmer might message Smith from home that evening. Smith's computer with braille output translates incoming e-mail, then relays her lengthy and exuberant responses.

This lady likes to talk, and the computer is her tool of liberation, giving her direct mind-to-mind access to the larger world.

"I've gotten to know who Janie is more from the e-mail than the bits and pieces we get out (at work)," Clemmer says.

The oldest of 5 children, Janie Smith is the only one in her family who carries the double-recessive gene that triggers Usher syndrome. Researchers estimate the disorder affects anywhere from 1 in 25,000 to 1 in 40,000 people. Some of the milder cases are never diagnosed. Smith has the rare, more severe form. Others are born with mild to moderate hearing loss and lose their eyesight at a slower rate.

No one suspected Smith was deaf until she was 9 months old when she failed to look up at her uncle's loud, playful greeting. Smith tells about it in a lengthy, autobiographical e-mail, using syntax that straddles standard English and the distinctive grammar of American Sign Language. She write, "My grandmother said to my parents that Janie's ears were not work right. They took me to see a doctor for exam

and he answered to my parents that I am profound deaf by birth to make my parents felt sad and real love for me."

On their doctor's recommendation they sent Janie to the John Tracy Clinic in Los Angeles where she enrolled in a free, therapeutic preschool for children up to age 5. The program, which stresses parent involvement and education, was founded in 1942 by Louise Tracy, wife of actor Spencer Tracy, 17 years after their infant son was diagnosed with profound hearing loss.

There Smith learned to lip-read and speak but not to sign, based on a belief - prevalent then - that learning to sign would prevent deaf children from assimilating into the hearing world. That philosophy is now controversial.

Although Smith's speech is hard for most people to understand, it's an important link to her mother, Patricia McDermott, who isn't fluent in ASL. "When I'm with her she talks all the time," said McDermott, 79, who lives in

Issaquah with her husband, Frank. "I can understand her."

Smith, who was born in Santa Monica, CA, spent her earliest school years in Los Angeles, first at the Tracy Clinic, then at an elementary school for deaf children. After the family moved to Orange County, she attended regular public schools where much of her instruction - including math and reading - was in mainstreamed classes. "There were no sign language interpreter ugh," she writes. "I just read teacher's lips sometimes it was difficult to read some people's lip was so thin ha ha."

In 11th grade, concerned that she wasn't being adequately prepared for college, Smith transferred to the California School for the Deaf in Riverside, where she learned to sign and was reunited with many of her friends.

At Golden West College at Huntington Beach, CA, she earned an associate degree as an office technician, then landed a clerical job at an insurance agency. Her employers liked

her work so much they spoke of hiring more deaf employees, to be placed under Smith's supervision.

Her career stalled after she married and moved to Pomona, CA. Unable to find office work there, she took a job as a power sewing machine operator. She and her husband had a daughter, Molly, now 22. Three years later she gave birth again...and again. "We thought I was pregnant with one," Smith says, "then out came another." Twins Cathy and Carrie weighed 4 lbs each and soon made their presence felt. "It was very overwhelming," Smith says. "I was busy all the time. But my mother helped me."

Smith's eyes had begun troubling her in college, but no one identified the problem. "I was fighting with the doctors," she says. "They kept telling me I was fine. I didn't think I was. People would wave to me and I would totally miss it. My family was concerned."

Smith was nearly 30, with 3 young

children, when a doctor finally diagnosed Usher syndrome. She and her parents were devastated. "I was so angry and saying why me and why me," Smith says. Her marriage ended a short time later and she collapsed into depression. Her mother says, "I was just frantic, trying to get her help."

Smith and her kids moved in with her parents, who were still in Orange County. They lived together for 5 years.

Before Smith's vision failed completely, the state of California and community organizations paid to send her to the Helen Keller National Center for Deaf-Blind Youths and Adults on Long Island, N.Y. There she learned the skills that would prepare her for a life without sight. She was at the Center for 10 months. "She learned to live as a blind person," says her mom, Patricia McDermott. "As a matter of fact, she had too much eyesight. They had to blindfold her to teach her."

It was an emotional time. For 6 months Smith rebelled at using a white cane because it made her feel "fully blind." "That means I did not accept my (declining) vision at all," she writes. Through counseling and support groups, which Smith calls "solve problems groups," she began the long process of reconciling herself to her genetic blueprint. The struggle continued through 16 years of gathering darkness. "Finally I accepted (it) two years ago," she says, "imagine that."

Although her psychological journey had just begun, Smith left the Helen Keller Center with the practical skills to take the first steps. She writes: "When I returned home from Helen Keller I felt a big change in my life not Janie anymore ha ha. I felt so good and happy to be able my own independently to travel by cane to ride bus and walk in malls..."

Smith's mother offered her a different kind of opportunity by posing a question: What is the one thing in the world you really want to

see before your vision slips away? "I'd like to go to Washington, D.C.," her daughter said. "I'd like to go to the White House and see President Reagan - all the things I've studied at school."

McDermott wrote to Nancy Reagan asking if there was any way her daughter could meet the president. Six days later they got a call inviting them to a celebrity-studded tennis match and dinner at the White House on May 24, 1981. The event was to thank companies that had support Nancy Reagan's "Just Say No" anti-drug campaign.

"Do you think you can come?" asked the first lady's secretary. They went, and were treated like royalty, starting with the spit-and-polish Navy guard who greeted them at the White House gate. "Janie could see him," her mother says, "and she absolutely died."

They sat front-row center at the tennis match, directly in front of the Reagans, then

queued to go through the receiving line to shake the "First Hands."



*To Patricia McDermott
With best wishes,*

Goucy & Ronald Reagan

The Navy band burst into tune as the guests sipped cocktails in the East Room and grazed at a buffet in the state dining room. At

7 that evening, when the party disbanded, Nancy Reagan's secretary approached the McDermotts with another invitation. "The President and Mrs. Reagan are going upstairs," she said, "and they would like to meet you and Janie personally."

"They were so wonderful and warm" Patricia McDermott says, "and they hugged me. I said, 'This has been the most wonderful day for Janie.'" That was the day Janie Smith turned 30.

One night in 1988, Smith accompanied a friend to a Halloween party in the San Fernando Valley. There she encountered Dan Smith, a man she'd known throughout her school years, since they were preschoolers at the John Tracy Clinic. They started dating and were married 10 months later at Fullerton, CA. Suddenly Smith's world expanded to include Dan and the 3 children from his first marriage, 2 of whom came to live with them. With her own 3 kids, it was a

full house.

Dan proposed, the story goes, after learning that Smith and her parents planned to move to Seattle, WA, where they had relatives. McDermott says Dan left a good job in California to be with the childhood friend he had grown to love. Three days after the wedding, they all moved to Seattle. Smith got a job at the Lighthouse for the Blind and worked there for 8 years, mainly operating a power sewing machine. Last year, with their kids out of the nest, Dan and Janie moved from a four-bedroom house in Bellevue to a town home at Port Orchard's McCormick Woods, where Dan can indulge his taste for golf. "They're just like honeymooners," says McDermott.

Last month the Smiths rendezvoused with some of their kids in Las Vegas, where Janie enjoyed the "very beautiful new hotels" and won \$135 at one of the casinos.

At Christmas the entire family - including

an infant grandson, Jared - gathered at their new home. Smith baby-sat one day while Jared's mom was in Seattle. "I had fun to have him smile," she writes. "He is happy baby."

McDermott, who used to drive her daughter to doctor appointments and other errands, says, "Janie has gotten so much more independent since she moved (across the Sound). It was hard to let her go, but I wouldn't have stopped her for anything in the world."

The most challenging part of Smith's day is the arduous commute from Port Orchard to Swedish. Wearied by 6 months of full-time commuting, she and Dan recently took a tiny apartment near downtown Seattle as a part-time layover, but they aren't sure they'll keep it. Port Orchard remains home base.

On commute days they leave home by 5:30 a.m. to catch either the Southworth or Bremerton Ferry to Seattle. Dan Smith then heads off to south Seattle, where he works as

an accountant. Janie Smith takes the bus - sometimes two buses - up First Hill with her guide dog, Maggie, a yellow lab.

Sometimes Smith, like the fictional Blanche Dubois, is forced to rely on the kindness of strangers. She carries printed cards, also labeled in braille, that tell passers-by what kind of assistance she needs - crossing a busy street, perhaps. Metro drivers are required to stop for people holding up bus-route numbers on the distinctive black-and-yellow cards that identify the deaf-blind. "They stop and open the doors for me," Smith says. "I feel the warm air. That's how I know the door is open." She hands the driver a printed card that explains where she needs to go and asks for a warning tap when her stop comes up. "Usually," Smith said, "the driver will shake my hand as I leave."

From there, Maggie guides her down the street and up the hospital steps. Smith holds Maggie's tail out of harm's way as they circle

through the revolving door. She leaves her backpack and coat in a room near the volunteer office, then pulls sterile scrubs over her black jeans and knit top.

This is where Maggie gets off. The yellow lab retires to a large kennel in the corner and patiently awaits Smith's return. Maggie used to bark mournfully, but volunteer coordinator Karen Stay says, "Now that she knows Janie will come back, she's OK."

Smith unholsters her collapsible white cane. It guides her to the sterile-processing room, located around the corner and one flight down. Inside the lab, she follows a trail of abrasive floor tape that was applied as a tactile guide to her work area.

Smith works intensely throughout the morning, plucking new supplies from carefully arranged bins and sorting through each drawer's leftovers for salvageable supplies. Her sensitive hands skim the piles searchingly, then strike like a hungry hawk.

When Smith approached Swedish about volunteer opportunities, no one was more surprised than her father, Frank McDermott, a hospital volunteer for 9 years. At 83, a year after open-heart surgery, he still assists one day a week in the pharmacy at Swedish.

"What possibly is there for her to do?" he asked Stay. Stay wasn't sure, but her background in occupational therapy - finding adaptive ways to master everyday tasks - made her a trained optimist. "There's got to be some way," she said. She hit pay dirt right away, when the Sterile-Processing department found a slot for Smith and made her one of their own.

"The staff love her," Stay says. "She's got a very good sense of humor. Just her body language - you can tell when she's tickled." Frank McDermott is proud of his daughter's gumption. "When she wants to do something," he says, "you just better accept it. I just hear nothing but good things about her around the

hospital."

Lunchtime, always welcome, is especially exciting this day as the department gathers for a holiday potluck. Cheek-by-jowl in a small meeting room, Smith and her co-workers heap their plates with pasta and green salads, sliced ham and dips. Smith savors a bit of holiday pie. "Pun-i-kin," she murmurs, recognizing the taste of pumpkin and spice.

A relaxed warmth fills the room as the gift exchange begins and wrapping paper goes flying. To "ooh's" and "aah's," someone holds aloft a gravy boat in the shape of a sleigh. Envious laughter greets someone else's trophy - a bottle of premier whiskey. Smith joins in the joke, placing hand on cheek in an expression of mock scandal.

Her own gift, courtesy of Clemmer, is a fluffy white snowman with a "carrot" nose and red and green muffler. Smith gives it an exuberant hug. "I love him!" she signs, reaching over to pat Clemmer's shoulder.

Everyone clusters for a Kodak moment. Smith, towering in the front row, jokingly bends her knees. At this gesture of humorous self-awareness, you wonder anew - is this amazing woman really blind? The answer comes a few minutes later, when she walks smack into a half-open door that you've failed to guide her around. A red welt appears on her cheek. Yes, she's really blind. And, boy, did you screw up.

As 4 o'clock approaches, Smith checks her braille watch more frequently. Dan is coming soon to drive her to the ferry. Working her way through an endless stack of drawers, she finally throws up her hands with a harried look that says, "Enough already; the rest can wait."

Back at the office, she greets Maggie and gives her some kibble before changing into her civvies. Breathing heavily, she fights to rethread a shoe lace that has slipped from a grommet of her gray hiking boots. With

Maggie in harness, they head for the elevator, where Smith presses both the up and down buttons. When a car arrives, she doesn't know which way it's going, but either way she'll eventually reach her destination.

Outside, in the gathering darkness and bitter wind, Smith carries out one of the most amazing feats of the day: When Maggie leaves her calling card on a patch of grass, Smith fits a plastic bag over her hand, bends down and deftly removes the offending deposit. She rolls the bag back over her hand, turning it inside-out, then ties a neat knot with an efficiency that borders on sleight-of-hand. She deposits the whole affair inside a paper bag.

Maggie whimpers from the chill wind, so they retreat to the vestibule. Dan Smith pulls up in a dark green Honda SUV. Tall and gray-haired, with a friendly manner, he leads his wife to the car and installs Maggie in the back. They wave and smile, then they're gone.

Smith's parents, who worked so hard to

smooth their daughter's path, have made peace with a diagnosis that once seemed so hopeless. "Have I accepted it?" Patricia McDermott asks rhetorically. "I had to, to help her." Frank McDermott proudly calls his daughter's accomplishments "just amazing."

Life goes on, as Janie Smith assured her mother recently when they met for lunch. "Mom," she said, "I can't see you anymore but don't be sad. I think this is the way God wanted me to be."

SHE'S A SURVIVOR

**By Glenda Farnum, Specialist on Deaf-
Blindness, Oklahoma Department of
Rehabilitation Services
Reprinted from HKNC UPDATE
Winter 2000**

**(Glenda Farnum, specialist on deaf-
blindness at the Oklahoma Department of**

Rehabilitation Services, is one of the HKNC affiliate family members. She relates the story of one consumer who has received local services through the cooperative efforts of her agency, HKNC Regional Representative CC Davis, and the State Vocational Rehabilitation counselors, Jane Nelson, who originally worked with Charolett, and her present counselor Tracy Vaughn.)

Charolett Nolte, an artist, professional storyteller, wife, and mother of three, was born with a moderate hearing loss. She wears a hearing aid in one ear and is deaf in the other. At age 30 she was legally blind.

"My hearing problem was something I was used to, but as I got older, the growing blindness made it difficult for me to use lip reading to supplement what I could hear," said Nolte. In 1986, she was diagnosed with Usher syndrome II, a condition which combines hearing loss with a progressive loss

of vision due to retinitis pigmentosa. At first, Nolte said she didn't feel angry about the diagnosis. It was more like a shock and a relief. But "when I was going to lose my freedom of driving, I had a spell of anger. I had moments when I was scared. Without my family, I wouldn't have made it."

Originally Nolte contacted HKNC Regional Representative C.C. Davis by mail, wanting counseling and information. "I suggested a visit with our affiliate, Glenda Farnum," said Davis. "I listened to Charolett's issues, offered information on adjustment to hearing and vision loss, discussed how to control one's environment and how to communicate, and talked about possible consumer groups. We chatted about the HKNC comprehensive vocational rehabilitation training program in New York, but she found it exceedingly difficult to consider moving so far away."

"Ms. Nolte is an excellent role model for people who mistakenly think that life is over

because you have a disability," Farnum said. "Sometimes it isn't easy, but she doesn't let it stop her. She walks where she wants to go, she paints, takes care of her family and does everything she wants to do."

Charolett found time to attend college at Oklahoma State University. With the help of a variety of adaptive equipment and tuition paid for by the State Department of Vocational Rehabilitation, which provided assistance with independent living, mobility and communication, she graduated in 1997 with a degree in art.

"Currently, Charolett is exploring the feasibility of earning money from the sale of her art work," noted Farnum. "She recently set up a booth at a craft fair to see how much interest her work would generate. We are working together through counseling and the provision of environmental signaling systems and other adaptive equipment. Charolett has learned the manual alphabet and is

considering learning some basic sign language. She has already received orientation and mobility services to increase her ability to travel safely in her community."



Glenda Farnum (l.) and
Charolett Nolte (r.)

Perhaps this story can best be concluded with Nolte's own words: "The important thing for me happened when I had this moment of realization - that I

can still do almost everything I did before. I just have to do it differently. I see myself as surviving!"

A DAY IN THE LIFE OF TROY

**Reprinted from HKNC UPDATE
Winter 2000**

PATH Day Program

by Mike Richards, Supervisor

(The Person-Centered Approach Toward Habilitation - PATH - is a transdisciplinary evaluation and training program designed to meet the needs of HKNC students who can benefit from a functional approach to learning. It includes methods and techniques that will assist a student to live as independently and creatively as possible in coping with every day needs and activities.)

Troy wakes to his vibrating alarm clock at about 7:30 am. He is not an early morning person, so sometimes he tries to roll over and ignore the alarm. With a tap on the shoulder and a signed "Good Morning" greeting from staff, Troy eventually arises from bed to begin

his morning grooming routine. He shares his room with a friend, and is adjusting to all the usual aspects of having a roommate including waiting for the bathroom, sharing personal space and respecting other people's belongings. Staff are naturally communicating these changes to Troy as they occur in his environment.

It takes Troy about 45 minutes to finish his grooming and then he initiates signing "eat." He independently finds his way to the group home kitchen where he prepares his breakfast. He independently collects his tray and the necessary utensils using the object symbols on the cabinets to assist him in locating items. He makes a food choice by manipulating the actual items and then is assisted by staff to cook a light, healthy breakfast. Troy enjoys contact with his peers and likes to check the table to see who is sitting with him. Staff encourage Troy to greet his peers and then join the group at the table for a very sociable

breakfast.

Around 9:30 am Troy is ready to head out for a challenging day of work. He checks the calendar board in his room to determine his work schedule for the day. The calendar has an object symbol representing the key work task for that day. Troy is familiar with these symbols and easily recognizes their meaning. He prefers some structured routines and the calendar facilitates his ability to anticipate his schedule.

Troy enjoys variety in his work activities. Twice a week he performs cleaning tasks at a local shoe store. Once a week he folds towels at a local hospital's laundry and on another day he works at Filene's Basement, unpacking and hanging clothing.



Troy prepares to hang shirts during his work activities at Filene's.

He enjoys all of these jobs, but seems to perform the best at stationary jobs such as laundry services or stocking clothes. Troy is able to work up to three hours at a time with a short bathroom break. He usually carries a lunch with him and eats in the staff cafeteria when he is off campus. Often on Fridays, when he receives his pay, he will enjoy lunch in the community with a staff member. His work day ends at 2 p.m.

PATH Evening Program

By Julie Tuifel, Supervisor

Troy arrives back at the residence at around 2 p.m. He is usually tired after his long day at work, so he requests some time to unwind in his room by making the letter "V" with his right hand and placing it on his left inner forearm. This is Troy's sign for "time in bedroom". Staff converse with him for awhile, asking him about his day and then he heads to his room. He trails the wall and

locates his room easily by the bottle of aftershave cologne that is attached to the door. Since Troy is a connoisseur of fragrances, this bottle represents something important to him.

After about one hour, Troy heads to the kitchen. He appears relaxed and refreshed. He investigates what his peers are doing and if there is anything going on. At this point he's a bit hungry, so he sets up his tray and looks for a satisfying snack. Staff offer him a variety of healthy options, but Troy knows what he wants. He dismisses the healthy snacks and locates the snack cabinet, identifiable because an empty potato chip container is attached to one side of the door and an empty cookie container to the other side. He uses his hands to search out the contents of the cabinet and locates something sweet, his favorite. He ambles toward the table, stopping if he feels something strange.

After a hearty snack, Troy goes food shopping. He thoroughly enjoys this activity

because he enjoys food. He sits at the table as staff describe to him what is needed today. Staff use sign language, paired with empty food containers, to express to Troy what is needed and use sign to show him a seat belt indicating it's time to go out. He picks up his coat from his room and returns to the kitchen to meet with staff. He's wearing his new leather jacket and is enjoying the fresh scent of it. Troy takes a staffer's arm. The sighted guide accompanies him to the van and the supermarket.

At the market, Troy matches the empty containers to new ones. He loves to explore the various textures and smells that the market has to offer and especially enjoys the fresh produce section where he chooses the week's



Troy is involved in a pre-food shopping exercise.

fresh vegetables. Troy picks up each vegetable, smells it, moves it around in his hand, and seems to be identifying the item. He has quite a sense of humor. He usually picks out vegetables that no one has ever heard of, such as butternut squash, turnips or coconuts, and then staff has to research how to cook them.

After shopping, it's time to prepare dinner. Troy puts on his gloves and apron to protect against germs, as he is cooking for his friends. Staff sit with Troy and cut up vegetables and Troy places them in a colander. He enjoys tasting a bit here and there to know exactly what he is preparing. Troy makes a drink from dry mix, uses the microwave to cook the vegetables and assists with setting the table. He may request the bathroom to indicate a need for a break.

After dinner it's off to Dunkin' Donuts for a cup of coffee and a low fat muffin. Troy has a clipboard with written print that reads "May

I have a small cup of coffee and muffin" and an empty Dunkin' Donuts cup. Troy knows that he needs to extend the clipboard to the clerk and that he will receive his coffee and muffin. He hands over money and waits with his palm up for change. Troy doesn't understand the various values of money, but he is learning that it is required for purchases.

After Dunkin' Donuts, Troy is ready for bed. He's had a long day and knows he needs to wake up early tomorrow. He can't wait until the weekend when he can sleep late and take it easy. With staff's assistance he sets his alarm clock for 7:00 a.m., and drifts off.

HERE AND THERE

A new 3-in-1 formulated shampoo is now available with a handy braille label. You'll never pick up the wrong bottle again when you are looking for shampoo! This product

combines all three steps in one bottle: shampoo, conditioner and hair rinse. To get more information or to order this new shampoo product contact: From B.L. Mitch with Love Hair Products 1-323-292-4562.

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TRAVEL MAGAZINE is a new publication available in braille and on cassette. This quarterly publication brings the world of travel to those who are unable to access print. Subscriptions are \$32.95 annually. For a sample copy, send \$1.00 for cassette, or \$5.00 for braille edition to: TRAVEL MAGAZINE, P.O. Box 24236, Cincinnati, OH 45225.

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The National Braille Press will offer electronic books called Porta-Books for portable braille devices. Porta-Books are books in braille format on disk that are designed for use with a portable braille reading device. Available titles are: "Harry Potter and the Sorcerer's Stone," "Charlotte's Web," "Safe Without Sight," "Cooking With Feeling: Adaptive Techniques and Recipes for Blind Cooks," "Captured by the Net," and "Shop Online the Easy Way." For more

**information, contact: National Braille Press,
88 St. Stephen Street, Boston, MA 02115
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Ann Morris Enterprises has a new web site at www.annmorris.com. Its new 2000 catalogue is available on web pages, or call (800) 454-3175 for a copy in large print, cassette tape or computer disk. The braille version costs \$10.00 or \$8.00 if specified as part of an order.

* * * * *

Tennnie Dietsch of Kentucky makes special mailers for cassettes or braille letters from naugahyde. The interior of the mailer is lined with fleece. Each mailer has velcro closure and a plastic clear window for reversible address cards. Mailers come in two sizes for

cassettes and one for braille letters. Sizes and costs are: cassette holder for one or two cassettes, \$3.00 for one or \$5.00 for two. Mailers that hold from three to five cassettes are the same price. Mailers holding braille letters measuring 10 by 12 inches are \$3.50 each. Make checks or money orders payable to Tennie Dietsch, 6434 Industrial Parkway, Calvert City, KY 42029 (276) 395-8391.

* * * * *

Sighted Electronics has developed Optical Braille Recognition (OBR). OBR is optical character recognition software that reads and translates braille into text for those who cannot read braille. OBR can read double-sided (interpoint) braille and single sided braille. It uses a conventional scanner. OBR runs on Pentium PC's with Windows 93 or 98 and a late version of the Hewlett-Packard scanner. For more information contact

**Sighted Electronics, 464 Tappan Road,
Northvale, NJ 07647 (800) 796-4883.**

* * * * *

Are you a diabetic? Do you have trouble finding sugar-free desserts? Sue Slater has created a guide to sugar-free desserts that can be found at restaurants and bakeries throughout the United States. This guide is available on the Internet at www.sugarfreesites.com.

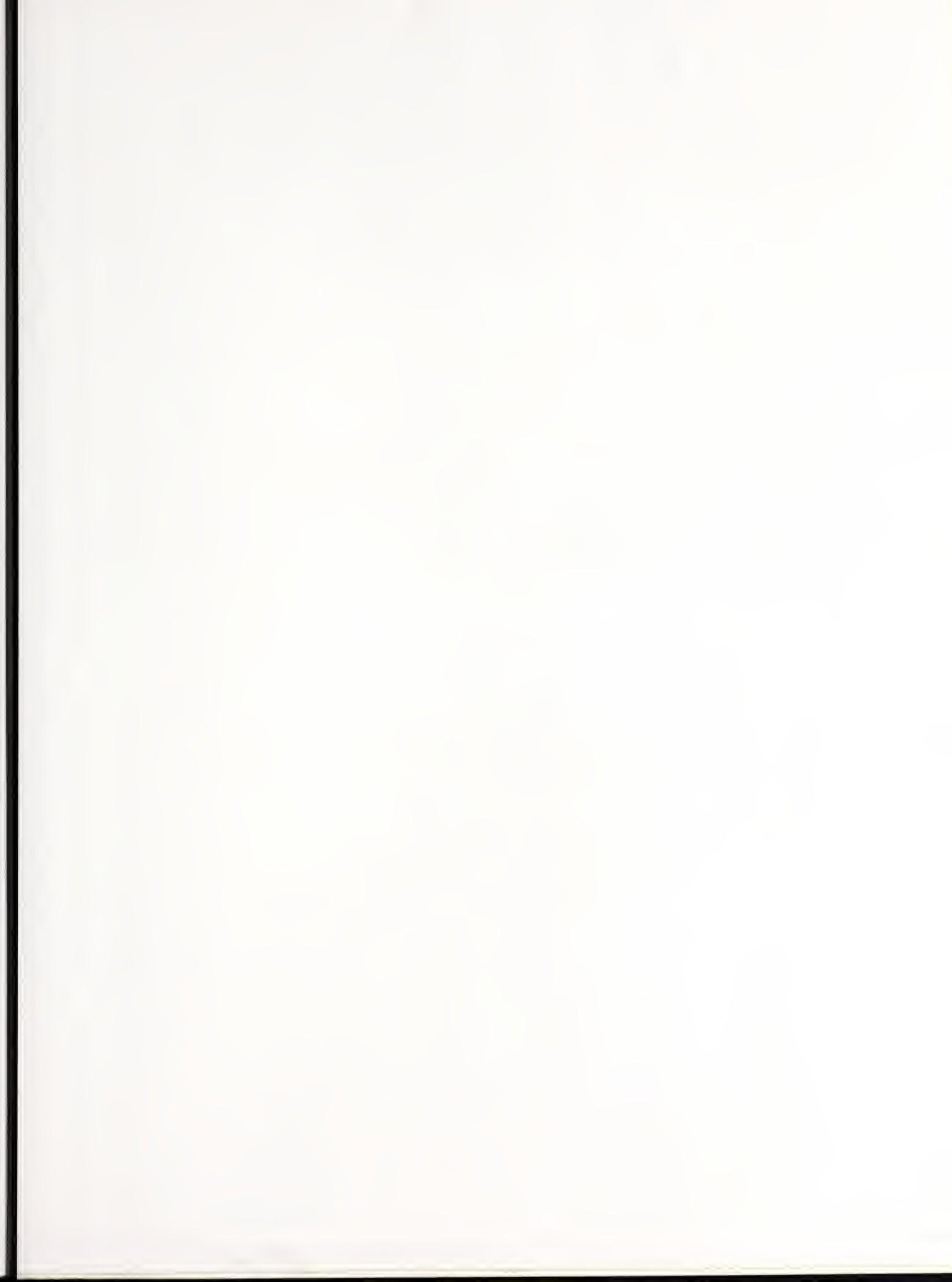
A LETTER FROM SUSAN SHAPIRO

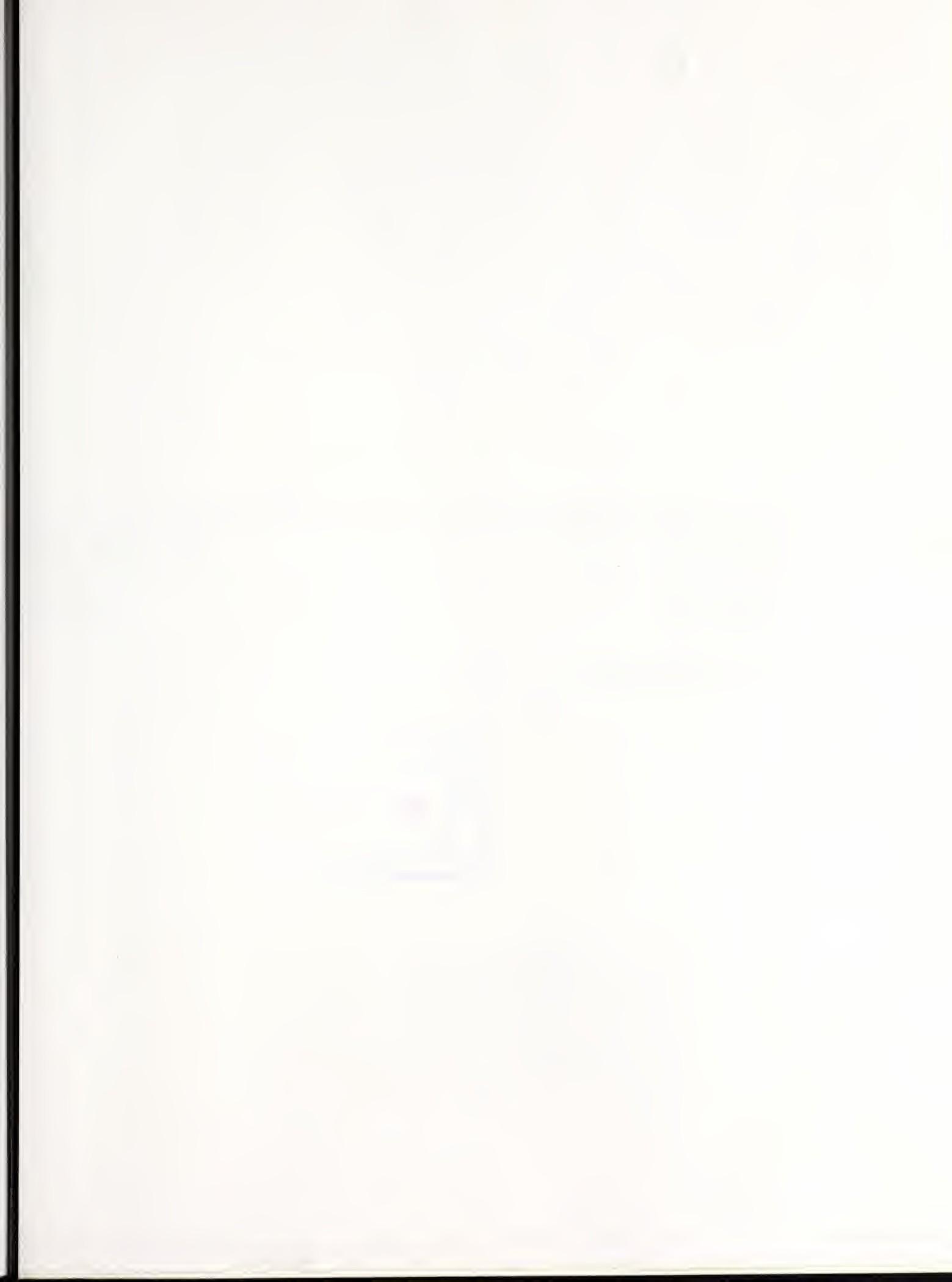
Editor's Note: Susan Shapiro is a former student and current volunteer at the Helen Keller National Center.

Dear HKNC Student and Past Students:

We invite you to join a directory of present and past HKNC students. It would let you

contact others who are deaf-blind, possibly finding past HKNC students living near you. Your privacy will be protected. The directory will be available only to HKNC students. If you are interested in being included in the directory, please contact Susan Shapiro at hkncalumni@aol.com or at the Helen Keller National Center, 111 Middle Neck Road, Sands Point, NY 11050. Thank you for your cooperation and we look forward to hearing from you soon.



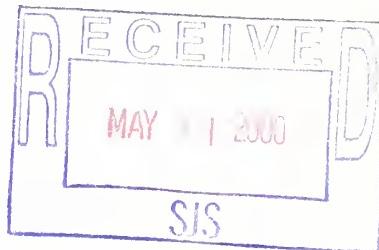


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